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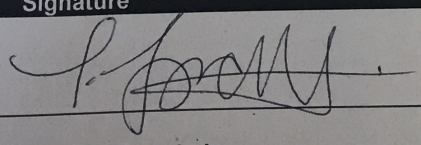	07/11/19

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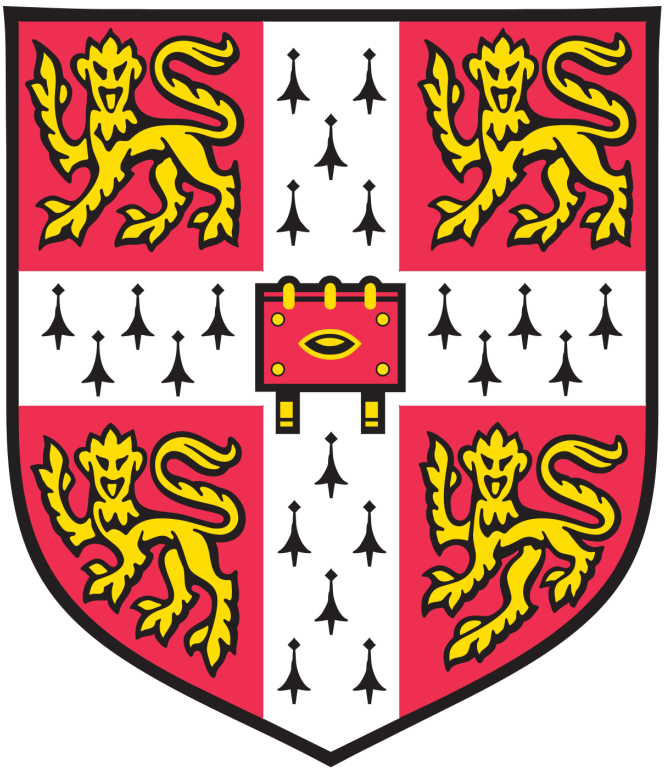
Social (In)Visibility and Disease Performativity: Qualitative Insights From Two US Case Studies



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Preface

This dissertation is the result of my own work and includes nothing which is the outcome of work done in collaboration except as declared in the Preface and specified in the text. It is not substantially the same as any that I have submitted, or, is being concurrently submitted for a degree or diploma or other qualification at the University of Cambridge or any other University or similar institution except as declared in the Preface and specified in the text. I further state that no substantial part of my dissertation has already been submitted, or, is being concurrently submitted for any such degree, diploma or other qualification at the University of Cambridge or any other University or similar institution except as declared in the Preface and specified in the text. It does not exceed the prescribed word limit for the relevant Degree Committee.

Abstract

This thesis centres on questions of (in)visibility in the lives of US "patients" with one of two chronic diseases (alkaptonuria and vitiligo). Specifically, it explores the role that social (in)visibility plays in the everyday lives of "patients" from both disease groups who experience their disease in relation to other social identities that they simultaneously occupy (including race, class and gender. In this thesis I conceptualise (in)visibility with respect to a wide range of issues related to the ways in which respondents exhibited and/ or failed to exhibit themselves and their diseases. Using grounded theory as a methodological framework, I collected data using a number of qualitative methods, including: semi-structured in-depth interviews, two ethnographies that took place at patient workshops in the US and the UK, and participant observation. This thesis consists of 4 empirical chapters that centre on issues pertaining to stigma, passing, pain and personal responsibility. Each of these issues is deeply embedded within narratives of how participants conceptualised their experiences of being "seen" and "unseen" in relation to their diseases, and speak to how those feelings are, in turn, informed by their disease's relative (in)visibility.

The first chapter, "Experiencing Stigma: Narratives of Precarity, Vulnerability and Loss," details the ways in which participants are routinely stigmatised because of their disease, and how their anticipation of stigma affects them on an everyday basis. The second chapter outlines the ways in which participants seek to conceal their disease from the public by masking their symptoms and/ or drawing attention away from them through the use of external objects. The third chapter considers pain as a non-visual signifier of "illness," and explores the ways in which experiences of being "seen" and/ or "unseen" in relation to their condition influences the participant's understandings of pain. My final empirical chapter considers how contemporary assumptions about the individual's ability to take responsibility for their health overlooks the financial, social and political restrictions that render many incapable of doing so. As a result, I argue that the individual is "invisibilised" within a system that stresses a need for personal responsibility whilst overlooking the individual's (in)capacity to assume it.

Name: Tanisha Jemma Rose Spratt

Title: Social (In)Visibility and Disease Performativity: Qualitative Insights From Two US Case Studies

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Introduction

> I am an invisible man. No, I am not a spook like those who haunted Edgar Allan Poe; nor am I one of your Hollywood-movie ectoplasms. I am a man of substance, of flesh and bone, fiber and liquids – and I might even be said to possess a mind. I am invisible, understand, simply because people refuse to see me. Like the bodiless heads you see sometimes in circus sideshows, it is as though I have been surrounded by mirrors of hard, distorting glass. When they approach me they see only my surroundings, themselves, or figments of their imagination – indeed, everything and anything except me. Nor is my invisibility exactly a matter of a bio-chemical accident to my epidermis. That invisibility to which I refer occurs because of a peculiar disposition of the eyes of those with whom I come in contact. A matter of the construction of their *inner* eyes, those eyes with which they look through their physical eyes upon reality.
>
> (Ellison 2001, p.3)

The above quote, taken from the prologue to Ralph Ellison's seminal novel *Invisible Man*, succinctly details the peculiar sensation of being and/ or feeling "invisible" when interacting with others in social spaces. For the narrator, his invisibility does not stem from the idea that he is "not there" in the world; he continues to exist as a corporeal being that is recognised as such by other people. Rather, it derives from the experience of being seen in a way that is unrelated to his individual subjectivity. When people look at him they see only his "surroundings, themselves, or figments of their imagination," which prevents them from seeing him as an individual. Upon encountering him they construct ideas about his personhood based on his physical characteristics, and from there they draw conclusions about who he is and choose not to investigate further. This, ultimately, prevents them from "seeing" him as an autonomous being, which renders him "invisible." The way that they view him is largely stereotypical. We soon after discover that this man is black, and his subsequent reflections on different episodes that have reminded him of his invisibility show how this experience is rooted in assumptions that were (and often still are) commonly made about black people. During the 1940s when this novel was written, these assumptions included the idea that black people were lazy, irrational, prone to violence, naturally unintelligent etc. (Tyree 2011; Siegesmund et al. 2019; Black et al. 2016). Because his body is immediately read in relation to these characteristics, the narrator's presence within these spaces is reduced to them. In this way, he unwillingly functions as a representative of a collective identity that is constructed in the public imagination, rather than as an autonomous being with his own interests, viewpoints and agendas.

The narrator's invisibility does not come from a personal feeling of *not having* a subjective will. He is very much aware of the fact that other peoples' failure to see him is a result of a problem with *them* and not *him*. It is a "matter of the construction of their *inner* eyes," which affects their ability to see him. In other words, it is not *what* they see in terms of their ability to register his presence upon encountering him, but rather *how* they see him that is the problem. In her work on the politics of invisibility Kath Woodward argues that "[l]ooking and seeing are embodied cultural and social practices which have material implications. What is visible does not lie only in what or who is viewed but also in the eyes of the beholder and the process of looking" (Woodward 2015, p.40). Thus, according to Woodward, how we learn to look and see is deeply embedded in our own social and cultural practices. We are taught how to look and how to see by the social and cultural environments that produce us, and this then informs the ways that we "see" others when operating in the world.

In this way, our conceptualisation of normative bodies and behaviours varies in accordance with our different social and cultural locations. As a person who was raised in a relatively small and predominantly white working-class town in the south of England, my understanding of what constitutes a "normative" body or type of behaviour likely differs considerably from the understanding that someone from a remote Caribbean island might have. In addition, our understanding of what is *not* "normal" is also likely to be considerably different. Because we both have an understanding of what "normal" *is* we also have an understanding of what "normal" *is not*, and this informs our treatment of those with whom we come into contact. It is important to note that our recognition of "normative" bodies and behaviour can (and typically does) shift depending on where we live. If I moved to a different part England and lived there long enough my understanding of what constitutes a "normative" body or type of behaviour would likely change. Thus, our understanding of what is "normal" is not only dependent on our upbringing but also on our exposure to different environments over the course of our lives.

Our conceptualisation of what is "normal" directly influences the ways in which we encounter and treat others. Because we already have an understanding of what being and/ or looking normal "is," we tend to respond to those who do not "look" or "behave" in a way that we deem "normal" in particular ways. Depending on the circumstances and the degree to which that person differs from our understandings of what constitutes being and/ or looking "normal," we might react with fear, apprehension, fascination or intrigue. As noted by Rosemarie Garland-Thomson in her work on the social phenomenon of staring, "[b]ecause we come to expect one another to have certain kinds of bodies and behaviours, stares flare up when we glimpse people who look or act in ways that contradict our expectations" (Garland-Thomson 2009, p.6).

Bodies that attract our attention because we understand them to be "unusual" typically show some outward sign of difference that initially compels us to look. After we look we often turn our attention away from fear of being seen to look by that person. Our decision to look away often comes from a feeling of shame or mortification for having singled out that person's "difference" and/ or, indeed, from having recognised that person as "different" in the first place (Kudlick et al. 2016). As noted by Garland-Thomson, "[e]ven though we like to stare, everybody knows we are not supposed to do it. Mothers scold gawking children. Etiquette manuals caution against untoward eyeing" (Garland-Thomson 2009, p.3). By showing that we have recognised them as "different," we reveal our understanding of what *constitutes* difference which, depending on how others in that particular social location view it, can lead to feelings of embarrassment or shame (Bonilla-Silva 2006; Nilsen & Turner 2014). An example would be a person who was raised in an openly homophobic community entering into a liberal space that was frequented by gay men and expressing shock or, potentially, outrage at the sight of two men kissing. Because that person's shock would likely be contrary to the reactions and opinions of those around him, he might deem it prudent to keep his reaction to himself from fear of being labelled an "outsider" in terms of his political leanings. Thus, depending on where we are, we are likely to avoid letting others know how we constitute difference if we fear being in the minority in terms of how we do so.

In a similar way, people who "look different" because of a disability or because they have a skin disorder that signals some type of medical condition might draw our attention in ways that we are embarrassed to show. This is because by doing so we would inevitably reveal our own biases in relation to our understanding of what constitutes being and/ or looking "normal." It is important to note that staring at that person and showing that one recognises them as "different" can (and often does) cause a significant amount of harm to that person, possibly resulting in them feeling alienated and highly self-conscious because of their appearance. Alternatively, it could lead to feelings of indignation in those who do not view their condition as self-defining and, thus, refuse to be reduced to it. For people with chronic conditions, their embodied experiences of living day-to-day with their condition and its symptoms means that they often learn how to carry out everyday activities despite the physical and/ or social limitations that it might cause (Charmaz 1997). By carrying on with life despite these challenges and by involving themselves in activities and experiences that are separate from their condition, they often recognise themselves as being *more than* their condition (Bury 1982; Williams 2000; Larsson & Grassman 2012; Aujoulat et al. 2008). Whilst they might view it as one aspect of their identity, they recognise that it is not the *only* aspect. In this way, being reduced to their condition by stares from other people can result in feelings of social invisibility amongst those who feel "unseen" in relation to

who they are (i.e. as people with interests, motivations, aspirations and subjectivities that are wholly unrelated to their condition).

This dissertation is a study of the social and political phenomenon of (in)visibility as it relates to the lived experiences of people with invisible and visible chronic diseases. For the purposes of this research I have chosen two chronic diseases as case studies, alkaptonuria and vitiligo. Alkaptonuria (hereafter AKU) is a rare genetic disease that causes the patient's bones and joint cartilage to turn black and, in some cases, disintegrate as they age and their symptoms progress. In addition to their bones and joint cartilage turning black, patients also typically experience dark sweat and urine. Neither the patient's urine nor their sweat "comes out" dark (i.e. they are not dark at the time of excretion), but rather *become* dark over time. This can (and often does) cause staining in clothing, bed linen, underwear etc., which can cause feelings of self-consciousness amongst patients who then attempt to hide these symptoms from public view.

Because it is genetic AKU is present from birth, and can be detected by parents if they notice their child's stained nappies and seek medical advice from a knowing medical practitioner. Other common symptoms include: dark earwax, dark pigmentation in the eyes, ears and hands, joint stiffness and chronic pain. Patients do not typically experience joint stiffness or chronic pain until they reach their late 30s, although it is fairly common for patients to report earlier experiences of both at different times during their late teens and throughout their twenties (Rovensky et al. 2015).[1] Because AKU is a rare disease (affecting roughly 1 in 250,000 – 500,000 people in the United States) doctors are often unfamiliar with it and, therefore, do not typically know what signs to look out for when trying to reach a diagnosis. This means that, after they experience the onset of symptoms like chronic pain, patients often go years without receiving a conclusive diagnosis. It is common for patients to be misdiagnosed with other conditions that are entirely unrelated to the one that they have, and to be sent to a number of doctors and medical specialists before a diagnosis is reached. Although dark pigmentation can sometimes be detected in the eyes of people with AKU, their symptoms largely go unnoticed. This, in turn, renders their disease "invisible" to those who fail to see common symptoms such as chronic pain, dark urine and dark sweat.

The second case study that I have chosen to use in this research, vitiligo, is an autoimmune disease that causes a sporadic loss of pigmentation on different parts of that person's body. This disease is often highly visible, particularly for people of colour,

[1] During their interviews numerous AKU patients discussed experiencing joint stiffness and chronic joint pain during their adolescent years and in their early to mid twenties, with some claiming that they could not remember a time when they did not experience either.

but has no known negative affects on that person's bodily health.[2] Its cause is unknown, with some specialists attributing it to a genetic predisposition in the person who has it, and others claiming that it is more likely related to stress, diet, lifestyle etc.[3] Whilst its affects do not negatively impact that person's health, it can be (and often is) psychologically devastating for those who witness their appearance changing and are unable to do anything to prevent it. It is common for people with vitiligo to experience a feeling of "loss" in relation to their identity. This is because, as their symptoms progress, it steadily becomes more difficult for some to recognise themselves in relation to who they once were in terms of how they once looked. Other than their visible loss of skin pigmentation people with vitiligo do not experience any other symptoms. Because this disease is relatively common compared with AKU (affecting roughly 1% of the world's population), doctors and dermatologists are typically familiar with it, which means that people who have it are significantly more likely to receive a speedy diagnosis than those with AKU. Like AKU, vitiligo is a progressive disease that commonly advances as the person ages, and can be exacerbated by incidents of physical or emotional trauma.

In using these two diseases as case studies, my thesis seeks to outline the role that disease (in)visibility plays in experiences of social (in)visibility, and how people from both disease groups manage these experiences on an everyday basis. The research questions that I address in this thesis are as follows:

i. In what ways and to what extent do people with AKU or vitiligo experience feelings of social (in)visibility because of their disease?
ii. How do people from both disease groups manage their everyday experiences of social (in)visibility?
iii. How does the relative (in)visibility of their symptoms affect their everyday experiences of living with their disease?

In addressing these questions, there are three primary ways that my thesis seeks to conceptualise (in)visibility. Firstly, in relation to the physical absence of those who have these conditions but remain unknown. As I will later discuss in my methodology chapter, at the time of writing there are no known African-Americans (and very few people of colour generally) who have been diagnosed with AKU in the US. Whilst this

[2] Whilst vitiligo is not known to have any negative effects on that person's physical health, during their interviews many participants drew connections between this disease and the incidence of other autoimmune diseases such as fibromyalgia. In this way they suggested that having vitiligo did negatively affect their overall health by making them more susceptible to other chronic conditions. In addition, one participant related her belief that the joint stiffness and pain that she had suffered throughout her life was directly related to her having vitiligo, and talked about similar experiences that she had heard from others within the online vitiligo community.
[3] When asked why they believe they developed vitiligo during their interviews, participants typically responded by attributing it to stress, lifestyle, physical trauma, diet and the fact that they had other autoimmune diseases and, thus, understood themselves to be more susceptible to it.

disease is rare, it is not one that is statistically more likely to occur amongst whites than amongst any other racial groups.[4] There are almost certainly African-Americans who are currently living with AKU without knowing that they have it, yet they are not being diagnosed with it and, as a result, are not receiving the specialist care that they need.

According to one leading AKU specialist, one of the reasons why African-Americans are not being diagnosed with AKU could be related to the visible presentation of some of its key symptoms: dark pigmentation in the eyes, ears and skin and chronic pain. Because dark pigmentation is often difficult to see on dark skin it may go unnoticed both by the people who have it and by the doctors who treat them. As previously stated, patients typically do not experience chronic pain until they reach their late 30s. From there, that person's pain often steadily increases as they age and their symptoms progress. Because joint pain is often considered by many to be a "natural" part of the ageing process, it is likely that many people who experience it overlook this pain and do not seek medical advice because they attribute it to the aging process. This, in turn, likely causes a decrease in the number of people being diagnosed with AKU. The second possible reason for a lack of diagnoses amongst African-Americans and people of colour more generally relates to potential racial biases amongst medical staff. Numerous studies have shown how the racial biases of medical staff can have serious affects on rates of diagnosis, medical care and treatment amongst people of colour (Tait & Chibnall 2014; Washingston 2008; Hoberman 2012). In order for doctors to diagnose patients with AKU they must first know what to look out for and then have an interest in carrying out further tests. If a doctor is uninterested in carrying out further tests because they either do not believe their patient's claims about chronic pain and/ or do not think that further testing is necessary, that patient is unlikely to gain a diagnosis.

For people with vitiligo, I conceptualise physical absence in relation to those who, because of their condition, remove themselves from public spaces and become reclusive. Numerous studies have detailed the negative effects that vitiligo can (and often does) have on the subject's mental health and well-being, and the ways in which it often causes those who have it to avoid social spaces entirely and remain at home either by themselves or with their families (Papadopoulos et al. 2002; Porter & Beuf 1991; Thomas 2007). As I will further outline in my methodology chapter, all of the people who agreed to take part in my research outwardly expressed confidence in their appearance and were keen to discuss their disease with other people. However, most also noted that they had, on numerous occasions, experienced prolonged periods of depression and/ or anxiety that caused them to purposefully isolate themselves from other people. By addressing the physical absence of people with vitiligo, I call attention to those people whose stories are unheard because of their on going struggles in coming

[4] Note that here I am specifically referring to the social determinants of health that often make it more likely that different racial groups will experience different diseases at different rates.

to terms with the effects of their disease, and the ways in which it prevents them from "speaking out" and relating their lived experiences to others (including me).

The second way that I am conceptualising (in)visibility directly relates to the (in)visibility of specific disease symptoms. I consider the ways in which the presence or absence of symptoms that can be seen by others influences the patient's personal experiences of social (in)visibility. In both cases, the visibility of their disease symptoms fluctuates in accordance with the individual's disease stage and their ability to effectively manage their symptoms. As AKU progresses and begins to affect the patient's mobility, patients are more likely to show visible signs of having a medical condition. Typically, their gait will be noticeably affected and they will have a slow walking speed. However, patients who were able to gain an early diagnosis as children do not commonly show outward signs of their disease until/ unless they reach this stage. As I will further discuss in my chapter on personal responsibility, patients who are able to financially afford to pay for drugs that minimise the physical effects of AKU are significantly more likely not to have noticeable signs of the disease as they age. Because these drugs minimise the damage that the disease causes to their joints and bone cartilage, patients who have access to them are considerably less likely to experience chronic joint pain and are less likely to have a noticeable gait as they age.

For people with vitiligo, the extent to which their depigmented area(s) of skin can be seen is largely dependent on where the affected area(s) of skin are and how able/ willing they are to cover it. For those who have noticeable depigmentation on their chest, stomach or thighs hiding evidence of their disease with clothing is relatively easy. However, for those who have depigmented areas of skin on their face, hands or neck their ability to conceal evidence of their disease is significantly more difficult. It often involves applying numerous cosmetic products to these areas during the day, and then consistently re-covering them as and when they wear off.[5] In addition, those who cannot financially afford these cosmetic products (which, in some cases, can cost upwards of $400 per month) are typically unable to use them. Because vitiligo is medically labelled a "cosmetic disease," medical insurers are often unwilling to cover the costs of treatments or products that minimise the disease's visibility. Therefore, the individual who has vitiligo is often responsible for covering the costs of both. As a result, the "wealthy" who are able to afford these products are considerably more likely to be able to successfully conceal their symptoms than those who are comparatively less wealthy and who cannot afford them.

[5] During their interviews participants often discussed at length their frustration with having to re-apply make up to affected areas at different times during the day. For those who covered the vitiligo on their hands, this meant reapplying every time they washed their hands and/ or came into contact with a physical object that they then touched.

The final way that I am conceptualising (in)visibility relates to the visible presence of people who have these conditions in physical and online spaces, both within and outside of their disease communities. After they are diagnosed it is typical for people from both disease groups to seek support from others who also have it through online communities or, if they are available, through support groups in their local area. Indeed, during their interviews, when reflecting on some of the positive experiences that have come from them having their disease, numerous participants claimed that it gave them a sense of "purpose" because of the advocacy work that they had done as a result of their involvement in these groups. For people with AKU, their presence in these spaces often provided them with the opportunity to be "seen" in relation to a condition that is "unseen" by those who do not know of it or do not also have it. By "becoming visible" as people with AKU, patients who choose to involve themselves in these communities are able to communicate their lived experiences of having the disease to listeners who might otherwise not know what living with it is like.

For people with vitiligo, their presence in physical and online spaces that are clearly earmarked for vitiligo advocacy work is often viewed as a way to build solidarity with others who have the condition as well as a key way to educate others about the disease. In making their body "seen" in these spaces, those who choose to do so typically seek to inspire others within the community to do the same, and to view the changes that vitiligo has made to their appearance in a positive way. By confidently displaying their depigmented areas of skin, these people seek to challenge common assumptions about vitiligo (i.e. that it is "disfiguring" and, therefore, unattractive) and suggest that it can, instead, be seen as something positive (i.e. as a visible sign of "uniqueness" and/ or "beauty"). In addition, many use this platform to educate others about the condition and correct misperceptions about its cause and affects (the most common of which is that it is both hereditary and contagious).

In this thesis I use the term "participant" when discussing people with AKU and vitiligo collectively. When I am referring to those with AKU I use the term "patient," and when I am referring to people with vitiligo I use the term "participant." I do so in order to represent each group in accordance with the way that they represent themselves. Many vitiligo participants expressly did not use the term "patient" when discussing their embodied experiences in living with the disease, and chose not to do so when referring to the interactions that they had with their doctors. This, they argued, was largely because they viewed it as a "disempowering" term that stripped them of agency and of their ability to "take pride" in the changes that the disease had made to their appearance. In addition, many of them did not regularly attend appointments with their doctors or dermatologists and, therefore, found this term to be inaccurate when describing their positionality. All of the AKU participants that I interviewed, however, routinely attended doctor's appoints and personally referred to themselves as patients.

They did not understand this label to be disempowering, but instead frequently used it to mobilise others within their disease group to make their voices "heard" by medical practitioners who, they argued, were there to "serve" them. I have also chosen to use the terms "disease" and "condition" interchangeably throughout this thesis as both were used synonymously by participants from both disease groups when describing their lived experiences.

Theoretical overview

The politics of social (in)visibility has long been a topic of academic interest for those concerned with the various ways in which bodies are read, interpreted, surveilled and regulated. In her book *Frames of War: When Is Life Grievable?* Judith Butler draws attention to the ways in which some bodies are considered "grievable" whilst others are not by highlighting the role that political power plays in determining which lives matter, and the role that social visibility plays in that determination. Using the example of Palestinian children who have been killed by Israeli soldiers in their pursuit of Hamas (a Palestinian Sunni-Islamist organisation), Butler argues that these children's lives were not considered "grievable" because they were not thought to be "lives" in the first place (Butler 2016, p.xxix). These children, she claims, were viewed as "human shields" because they protected Hamas from Israeli fire and, as such, were seen by Israeli soldiers to be "not children at all, but rather bits of armament, military instruments and material, aiding and abetting an assault on Israel" (Butler 2016, p.xxvi). Viewed as collateral damage in the on-going fight between Israel and Hamas, these children were reduced to their positionality as "military instruments" that seemingly "protected" those who posed a threat to Israel. Their political powerlessness within this conflict meant that their deaths did not "matter" to those who caused them, which meant that they were seen as "instruments," rather than victims, of war.

By using the deaths of these children as an example, Butler shows how the ways in which our bodies are interpreted (in this case as "military instruments") greatly affects our position as subjects and, even, our chances of survival. She further shows how the "disposability" of some is inextricably linked to their positionality as politically marginalised subjects, which, in turn, results in their erasure from narratives that centre bodies that *are* "grievable" as the primary cites of mourning. This erasure, Butler argues, constitutes a type of invisibility, whereby those who are "unseen" remain so to members of the public because visual depictions of state-sanctioned war-efforts purposefully create narratives that render the lives and suffering of the "ungrievable" unknown. Using media reports of 9/11 as an example, Butler argues that, after these attacks, "we encountered in the media graphic pictures of those who died, along with their names, their stories, the reaction of their families. Public grieving was dedicated to making these images iconic for the nation, which meant of course that there was

considerably less public grieving for non-US nationals, and none at all for illegal workers" (Butler 2016, p.39). By tying images that depict those who are "grievable" to ideas of "the nation" and how it is imagined, Butler argues that our centring of those who are seen to "matter" necessitates a de-centring of all of the lives that were lost and/ or affected by tragedies like 9/11 that seemingly "do not matter." By highlighting the importance of *some*, Butler argues, we exclude the importance of *others*, which often renders the latter invisible within narratives that report large-scale incidents of tragedy and/ or violence.

In their book *Missing Bodies: The Politics of Visibility* Monica J. Casper and Lisa Jean Moore make similar claims to Butler by drawing attention to the ways in which some bodies are "seen" whilst others remain "unseen" in different social and political locations. Drawing on theories concerning biopolitics and what cultural studies theorist Henry A. Giroux labels the "politics of disposability" (Giroux 2006), the authors argue that "because society is stratified along lines of gender, race, class, sexuality, age, disability status, citizenship, geography, and other cleavages, some bodies are public and visually dissected while others are vulnerable to erasure and marginalisation (Casper & Moore 2009, p.9). Thus, according to these authors, the social stratification of different people in accordance with factors that are largely outside of their control (i.e. race, disability status and citizenship) render some bodies "seen" and others "unseen" depending on the social and political attitudes that others hold within their particular social location. Through their work, Casper and Moore seek to recuperate "missing bodies and the circumstances of their erasure" in order to offer a holistic interpretation of the role that social and political invisibility plays in deciding which lives matter and which seemingly do not. This, they acknowledge, is both a political task and a methodological challenge. Measuring the "absent subject" involves "looking beyond" what one knows in order to uncover the "unknown" and, potentially, "unknowable." "How," they ask, "do we enable bodies that are muted in or by public discourse to speak in their own terms? In other words, how do we as scholars come to understand the missing if their lives and indeed their very corporeal essence are systematically ignored, erased, unseen, or missing in action?"(Casper & Moore 2009, p.14).

In order to meet these challenges both authors propose using what they label an "ocular ethic," which might enable the forging of a "new legacy of looking: one that refuses to assign political value to some bodies at the expense of others, one that treats 'human subjects' in the fullness of their lived, embodied experiences"(Casper & Moore 2009, p.14). This "ocular ethic" includes three principle elements: "focusing, magnification, and visualising." "Focusing" involves drawing attention to the "analytic gaze" that is often employed when visualising the "often-marginalised bodies, individuals, and groups in social life" (Casper & Moore 2009, p.15). By "focusing" on the ways in which

historical legacies of social and political marginalisation inform our ways of seeing, the authors argue that it is possible to see these groups "in situ and on their own terms" (Casper & Moore 2009, p.15). By magnifying those experiences (primarily through the use of ethnographic methods) we would be able to "reveal, resituate, and recuperate" their narratives (Casper & Moore 2009, p.15). Moreover, by engaging in practices that would allow us to both "focus" on and "magnify" their lived experiences, we would be able to situate their embodied experiences within narratives that have systematically marginalised and excluded them. This, the authors claim, would allow those who were previously "invisible" to *become* "visible" in social and political conversations.

Alongside the literature that deals with "absent" or "missing" bodies from social and/ or political discourse, numerous scholars who are interested in the political dimensions of social (in)visibility have focused their attention on the underlying reasons and motivations for our individual invisibility. These scholars often assess the role that social (in)visibility plays in the lived experiences of individual people, highlighting the personal motivations that individuals have to *become* visible or invisible based on their social locations and/ or political leanings. Originally published in 1902, Charles Horton Cooley's theory of "the looking-glass self" offers a useful way of conceptualising how and why we often routinely shape our behaviour and/ or our appearance in accordance with our anticipation of how others will see us. According to Cooley, "[as] we see our face, figure and dress in the glass and are interested in them because they are ours, are pleased or otherwise with them according as they do or do not answer to what we should like them to be; so in the imagination we perceive in another's mind some thought of our appearance, manners, aims, deeds, character and so on, and are variously affected by it" (Cooley 2009, p.184). In this way, when we see reflections of ourselves our interpretation of our appearance is always seen in relation to others and, more specifically, to our anticipation of how we will be perceived by those others upon meeting them.

Moreover, according to Cooley, because we constantly apprehend how others will view us, we continuously shape our "appearance, manners, aims, deeds" etc. in order to suit what we think others will expect, enjoy or appreciate from us. In this way our bodies and our appearance are never wholly ours, but are always "shared" by those who (often unknowingly) shape it by creating in our minds an understanding of how they will read us. When outlining the specificities of the "looking-glass self" Cooley argues:

> A self-idea of this sort seems to have three principle elements: the imagination of our appearance to the other person; the imagination of his judgement of that appearance, and some sort of self-feeling, such as pride or mortification … The thing that moves us to pride or shame is not the mere mechanical reflection of ourselves but an imputed sentiment, the imagined effect of this reflection upon

> another's mind. This is evident from the fact that the character and weight of that other, in whose mind we see ourselves, makes all the difference with our feeling. We are ashamed to seem evasive in the presence of a straightforward man, cowardly in the presence of a brave one, gross in the eyes of a refined one and so on.
>
> (Cooley 2009, p.184)

By outlining what he perceives to be the three "principle elements" involved in how we shape our bodies in accordance with the views and opinions of others (imagining how others see us, imagining how they judge us based on how they see us, and the "self-feelings" that come from our response to those judgements), Cooley shows how our decision to mould our appearance and/ or behaviour is the result of a process of *self-realisation*. We first have to imagine how we will be seen before we can shape our behaviour/ appearance accordingly, and we do so knowing what our likely "self-feeling" will be if the way that we are seen generates an opinion of us that is unfavourable. Arguing that we are "ashamed to seem evasive in the presence of a straightforward man, cowardly in the presence of a brave one [and] gross in the eyes of a refined one" Cooley infers that we routinely alter our behaviour and/ or appearance in accordance with the characteristics of those we will be seeing. Because, depending on where we live, we often regularly interact with a range of different people, this would mean constantly modifying and/ or adjusting our behaviour/ appearance throughout the day in an effort to encourage positive reactions from all of the people we meet.

Whilst Cooley is undoubtedly correct in his assertion that we are routinely aware of how others perceive us when interacting in social spaces (indeed, our awareness of possible threats from others in response to our appearance/ behaviour often warrants constant vigilance with regards to the way that we look),[6] his theory fails to account for those who purposefully make themselves "look different" in order to "shock" or challenge normative ideas of what bodies "should" look like. Numerous scholars have drawn attention to those groups of people who intentionally display or "make known" visible "differences" in order to emphasise the limited and restrictive frame that delimits who is deemed "normal" or "acceptable" and who is not. Butler's use of drag as an example of the deconstruction of gender categories offers a clear example of this. When discussing the (de)construction of gender categories that associate what it means to be "male" or "female" with specific practices and behaviours, Butler argues that drag "fully subverts the distinction between inner and outer psychic space and effectively mocks both the expressive model of gender and the notion of a true gender identity" by

[6] As I will discuss in later chapters, during their interviews several participants from both disease groups reported feeling uneasy about their appearance when they knew that it would likely be mistaken as a sign of "deviance" or "self-neglect" by unknowing onlookers. As a result, many chose to modify their appearance and hide visible signs of their disease in order to ward off negative attention.

showing how normative understandings of gender are challenged by those who, through their bodily presentation, do not fit neatly into either category (Butler 2006, p.186). In purposefully seeking to deconstruct these categories, Butler argues that those who perform drag do so, in part, in order to *challenge* the normalising gaze that cannot place them. Knowing that they will likely encounter others who are not fellow drag artists, those who perform drag are unconcerned with measuring themselves in relation to others around them, but rather purposefully seek to "look different" in order to challenge those others to think differently.

Whilst it is easy to critique Cooley's theory in this way, it directly relates to ideas put forth by subsequent social theorists about the malleability of bodies and the ways in which they can be shaped to meet broader social and/ or political aims. Michel Foucault's conceptualisation of "docile bodies" that are moulded and regulated by operating forces is a useful and often cited example by social scientists working within the field of visual or cultural studies. When outlining what he means by the term "docile bodies," Foucault argues that a body is docile when it "may be subjected, used, transformed and improved" and that these bodies are produced through the use of regulatory forms of discipline (Foucault 1995, pp.136–138). "Discipline," Foucault argues, "increases the forces of the body (in economic terms of utility) and diminishes these same forces (in political terms of obedience)" and in doing so "dissociates power from the body" (Foucault 1995, p.138). "[O]n the one hand," he argues, this disassociation of power turns the body "into an 'aptitude,' a 'capacity,' which it seeks to increase, and "on the other hand, it reverses the course of the energy, the power that might result from it, and turns it into a relation of strict subjection" (Foucault 1995, p.138). In line with contemporary understandings of the role of neoliberalism in shaping and constructing "productive" citizens (Pienaar 2016; Galvin 2002; McGregor 2001), this form of discipline seeks to utilise bodies in ways that are beneficial for the operating power (i.e. the state).

"Docile bodies" that are formed, constituted and utilised by disciplinary powers to meet the needs of those powers contribute to the discussion of social (in)visibility by highlighting the significance of social and/ or political hierarchy in determining the degree to which one is "shaped" and/ or controlled. Whilst we are all, to some extent, shaped by organising forces that are outside of our control, some bodies are acted upon more than others, which renders them more prone to invisibility within systems and/ or organisations that erase their subjectivity in favour of making them "useful" subjects and/ or commodities. Factory workers are more likely to be "invisibilised" in this way than factory owners, and factory owners are more likely to be "invisibilised" than shareholders who hold greater sway in the general management of the factory. In democratic societies that elect leaders based on their capacity to govern, those who elect and are governed regularly shape the ways in which their leader(s) govern through

political mobilisation in the form of strikes, protests and/ or civil unrest (O'Donnell 2010). This, in turn, holds those leaders accountable to a regulatory "gaze" that routinely shapes their behaviour and political decisions.[7]

Foucault's understanding of the malleability of bodies in relation to the "regulatory gaze" that controls and/ or polices them can further be understood in relation to W.E.B Du Bois's earlier theory of "double consciousness." Writing in 1903, Du Bois describes "double consciousness" as a "feeling" or "response" that black people have to the experience of being "unseen" in relation to the way that they see themselves:

> After the Egyptian and Indian, the Greek and Roman, the Teuton and Mongolian, the Negro is a sort of seventh son, born with a veil, and gifted with second-sight in this American world, - a world which yields him no true self-consciousness, but only lets him see himself through the revelation of the other world. It is a peculiar sensation, this double-consciousness, this sense of always looking at one's self through the eyes of others, of measuring one's soul by the tape of a world that looks on in amused contempt and pity. One ever feels his twoness, - an American, a Negro; two souls, two thoughts, two unreconciled strivings; two warring ideals in one dark body, whose dogged strength alone keeps it from being torn asunder.
>
> (Du Bois 2018, p.3)

According to Du Bois, blacks in the US are denied any form of "true self-consciousness" because they primarily see themselves in relation to the way that others see them. This mode of viewing is constituted by the white "other," and offers a reductive reading of the black subject based on his or her physical characteristics and the negative connotations that the white "other" associates with it. We might think here about Ellison's invisible man, and the idea that he remains "unseen" because others "refuse to see" him as they cannot/ choose not to look past his appearance and what it supposedly suggests about him (i.e. that he is a representative of a broader consciousness that is embodied by all black people). According to Du Bois, because the white "other" is in a position of power they constitute the "dominant" gaze, and this renders the black subject "malleable" and "vulnerable" to the internalisation of that gaze. As a result, the black subject is coerced into seeing themselves "through the eyes of the other" and of "measuring [their] soul by the tape of a world that looks on in amused contempt and pity." Because the black subject has "two souls" (an "American" and a "Negro") that cannot be reconciled in a racist society that renders them mutually exclusive, he/ she

[7] Note that this is not always successful. Political leaders can be (and often are) unresponsive to civil unrest.

"ever feels [their] twoness," and this renders them "invisible" to those who cannot view them as a whole.

When conceptualising the relationship between (in)visibility, health and chronic illness, philosopher and former medical practitioner Drew Leder argues for an understanding of (in)visibility that considers the phenomenological standpoint of the individuals who experience it. Drawing attention to particular bodily sensations that make specific regions of the body "known," Leder argues that we are continuously "unaware" of our bodies in a way that renders them "invisible" to us. "The body," he argues, "emerges at times when it is away from an ordinary or desirable state, as in times of pain and disease. The body then may be experienced as away, apart, from the 'I'" (Leder 1990, p.90). According to Leder, unless we experience a particular sensation that draws our attention towards our body (such as pain) we tend not to "see" our bodies in their entirety. Moreover, because these sensations typically arise in specific parts of our bodies, whilst we are focusing on them we are likely unaware of the other parts of our bodies that are not causing us pain. In this way, a number of different parts of our body remain "invisible" to us at any given time, depending on the particular sensations that we are feeling at that moment. Leder conceptualises this form of "invisibility" as a type of "dys-appearance," and distinguishes it from "disappearance" by considering it in relation to the seemingly opposing experiences of "health" and "illness:"

> Health and illness can be taken as examples of the two complemental poles. Both exhibit an element of alienation from the body. In the case of health, the body is alien by virtue of its disappearance, as attention is primarily directed toward the world. With the onset of illness this gives way to dys-appearance. The body is no longer alien-as-forgotten, but precisely as-remembered, a sharp and searing presence threatening the self. One is a mode of silence, the other a manner of speech, yet they are complementary and correlative phenomena.
>
> (Leder 1990, p.91)

According to Leder, when we experience prolonged periods of "health" we temporarily "forget" our bodies in relation to how they function on a day-to-day basis. Consequently, our bodies "disappear" as we draw our attention towards phenomena that exists outside of our bodies. As I will later discuss in my chapter on pain, during their interviews both AKU and vitiligo participants routinely discussed how, when they were distracted, they temporarily "forgot" the areas of their body that were causing them emotional or physical pain. On the other hand, "Dys-appearance" occurs when we experience illness and our bodies become "alien as-remembered" because we fail to recognise them in relation to the way that we previously experienced them. By

presenting us with new sensations that draw our attention to the particular areas of our bodies that are affected, "illness" magnifies areas that were previously "invisible" to us because they were unfelt.

Closely tied to issues related to the politics of (in)visibility are those relating to the social and political phenomenon of performativity. Performativity describes the processes through which social descriptions and labels that hold no inherent truth or meaning *become* "true" through the use of reiterative practices that ascribe meaning to them. Using gender as an example, Judith Butler outlines performativity in the following way:

> [A]cts, gestures, and desire produce the effect of an internal core or substance, but produce this *on the surface* of the body, through the play of signifying absences that suggest, but never reveal, the organising principle of identity as a cause. Such acts, gestures, enactments, generally construed, are *performative* in the sense that the essence or identity that they otherwise purport to express are *fabrications* manufactured and sustained through corporeal signs and other discursive means. That the gendered body is performative suggests that it has no ontological status apart from the various acts which constitute its reality.
>
> (Butler 2006, p.185)

According to Butler, the "internal core or substance" that we believe constitutes gender is, in fact, produced by "acts, gestures, and desire" that we perform in order to convey our understanding of gender. Moreover, because this understanding is socially and politically constructed it has no inherent "truth," value or meaning, and is wholly subject to our reiterative performances of it. Female children who, at a young age, express an interest in playing with dolls and kitchen sets do not do so because of an innate interest in these objects, Butler suggests, but rather because they have been socialised to believe that they *should* show an interest in these things because of their gender. In a similar way, male children who express an interest in playing with action figures and toy guns do not do so because they naturally prefer these objects, but rather because they have been socialised to believe that these objects are appropriate for them to play with as young boys.

Thus, according to Butler, performativity describes the performances that we enact in order to reify identities that have no inherent meaning. In this way, performative acts emphasise the socially constructed nature of identities that we take for granted. This argument contributes to the literature on invisibility by outlining the ways in which our "true" identities can (and often do) become hidden behind our performances of other identities that may be deemed more socially or politically "acceptable." The female

child who has an interest in playing with action figures and toy guns might, depending on her age, purposefully choose to play with dolls and kitchen sets in order to please the adults around her who expect her to perform her gender in this way. This act would not detract from her interest in playing with action figures and toy guns, but it would allow her to pass as "normal" when around those adults and, thus, keep this interest hidden from them. As this example illustrates, performativity can be viewed as a phenomenon that facilitates passing and, thus, enables social invisibility. As I will further outline in each of my empirical chapters, passing and the ways in which it relates to the phenomenon of social (in)visibility is a key component of this thesis. By concealing their feelings and everyday struggles with regards to stigma, pain and feeling "personally responsible" for their inability to effectively manage their disease, I argue that participants from both disease groups are left feeling socially invisible to those who are unable to know or relate to their lived experience of disease.

Methodology

Forming the Research Project

When I first began this research project I did so with the intention of focusing on AKU as a single case study. I initially became interested in AKU when I saw that there was a call for a PhD researcher to consider the role of ethnicity in the everyday lives of patients with this disease. The call specified that AKU is genetic, and that it is more likely to be found in "ethnic minority communities" where consanguineous relationships are "more common." Because of my former interest in the relationship between stigma, race and ethnicity the tone of this call immediately struck me. I thought it presumptuous at best to assume a direct correlation between ethnicity and consanguinity, and considered it highly problematic that ethnicity and disease were being linked in this way. Nevertheless, I was interested in the experiences of patients with this rare genetic condition, and was keen to find out how living with AKU might influence their everyday experiences and interactions. I was curious to discover whether patients were aware that researchers were making a link between ethnicity, consanguinity and AKU, and (if they were) how they felt about it. At this point in the project I chose to focus on African-American AKU patient experiences in particular, as I was familiar with the historical legacy of abuse that African-Americans have suffered in clinical settings and was keen to explore this issue further in relation to AKU.[8] I was particularly interested to know if a widespread cultural mistrust of orthodox medicine influenced the decisions that African-Americans AKU patients made in relation to their treatment options and medical care.

Soon after I began this study, a leading AKU medical expert from the AKU Centre in Liverpool, UK contacted me and offered his help with my initial enquiries. I asked him if he knew of any patient support groups within the US that were formed by, or primarily consisted of, African-Americans and, to my surprise, he responded by saying that he was not aware of any African-Americans who had been diagnosed with AKU.[9] He then reached out to colleagues in the US and in Canada to find out if they knew of any African-Americans with AKU, all of who responded by saying that they did not. Because AKU is a rare condition (affecting roughly 1 in 250,000 – 500,000 people in the US) patients who are diagnosed with it by their primary care physician are referred to AKU specialists at the National Institute of Health (NIH) in Bethesda, Maryland for further advice on everyday disease management practices, treatment options etc. From there, patients are typically monitored and told what

[8] For further reading about African-Americans and the historical legacy of medical abuse see (Washington 2008).
[9] Note that because they are often thought to have different challenges and experiences, it is not uncommon for African-Americans and/ or minority patients to form their own patients support groups in the US.

exercise routines and diets would suit them best. Because several of the specialists that responded to his initial enquiry by saying that they did not know of any African-American patients were AKU specialists who worked at the NIH, I concluded that it was highly unlikely that any African-Americans had, at that time, been diagnosed with AKU. As one specialist later told me "if they had, we probably would have known about it." After an extensive literature review in which I attempted to uncover evidence of any reported cases of African-Americans with AKU I came across one study from 1941, entitled: "Alcaptonuria in a Negro family" (Abbott Jr. 1941).[10] The author of this study, Lynn D. F. Abbott Jr., stated that, up until that point, "Alcaptonuria in the American Negro [had] never been reported" and that she was the first person to have found positive cases in siblings aged 8 and 13 in Virginia. In her assessment of the two children she concludes that they " appear healthy and well nourished" and "are typical American Negroes in every respect" without offering any further clarification or evidence to support these claims (Abbott Jr. 1941, p.366). At the time of writing, this is the only study that has addressed the incidence of AKU in African-American patients.

After speaking to a number of doctors and health care professionals about the low rates of AKU diagnosis in the US amongst people of colour in general, and African-Americans in particular, I began to consider the possibility that this was likely the result of a lack of access to good quality health care. In order to be diagnosed with AKU patients must first have a primary care physician who is familiar with the disease and knows what symptoms to look out for. Knowing this, I considered it highly likely that the reason why some people were not being diagnosed was because they did not have a primary care physician who had heard of it. This, of course, would mean that those patients would not reach the attention of the AKU specialist team at the NIH who regularly monitor patients and keep records of the number of people who have been diagnosed. This was later confirmed during an interview with the leading specialist in this team, who stated that health care providers had to first have "an interest in the disease's symptoms" for it to be identified. Medical providers who are unaware of what the symptoms are and/ or who are reluctant to carry out further tests, she argued, are likely to be the reason why some patients are not being diagnosed.

Statistics show that the incidence of AKU does not vary according to race in the US (Health 1861; Aquaron 2011), which means that it is fair to surmise that there are currently undiagnosed African-Americans who are living with AKU. When I initially came across this finding it opened up an entirely new avenue of social visibility within my research, and led me to question the role that the "absent presence" of African-Americans has within this study. Knowing that I could not interview African-Americans with AKU, I was aware that I would be unable to relate their lived experiences in dealing with it. Moreover, I also knew that I would be unable to talk about their experiences in relation to the experiences of white patients,

[10] Alkaptonuria was commonly spelt alcaptonuria in the early twentieth century when Abbott Jr. was writing.

which, in turn, would mean that I would be unable to discuss any racial and/ or cultural differences in terms of coping mechanisms, strategies etc.

I chose to conduct a comparative study between AKU and vitiligo roughly 2 months after I began the PhD. This decision was the result of the work that I had done to uncover more about the aetiology of AKU, and the ways in which it visibly presents itself on the patient's body. At this point I was principally concerned with how patients coped with having these visible symptoms, and whether or not they were routinely stared at and/ or stigmatised when in public spaces because of them. After learning that AKU is a largely invisible disease and can be hidden with relative ease by covering areas of depigmented skin with hair, clothing etc., I turned my attention to the ways in which its relative invisibility affects the ways that patients cope with it. Having read a number of accounts from people with invisible chronic conditions like diabetes and lyme disease, I began to question whether having an invisible chronic condition like AKU made it easier to live with because it did not attract a great deal of attention, or whether it made it more difficult for patients who were constantly "unseen" in relation to their daily struggles in living with it (Metzger 1997; Cashel 2015; Khakpour 2018). Did AKU patients, I wondered, prefer having a condition that did not prevent them from "looking normal"/ "healthy," or would they have preferred to have a visual recognition of their difference so that their claims about pain and fatigue were more readily understood and/ or believed by other people?

I then began to think about people with conditions that did the exact opposite, i.e. ones that were *seen* and not *felt*. How did the experiences of AKU patients compare with the experiences of people who had highly visible conditions but did not feel any bodily affects or symptoms? These people, I assumed, would routinely draw attention from onlookers, some of who might wrongly assume that their visible symptoms were indicative of their overall "poor health." I anticipated that this might generate a different type of frustration to the one expressed by people with invisible chronic diseases, wherein people with highly visible conditions might feel frustrated and/ or angry at this misconception because of how it differed from their embodied experience of "feeling fine" despite "looking different." Whilst I was conducting a preliminary literature review I came across vitiligo. I was already somewhat familiar with this condition, having heard that Michael Jackson had it as well as other known celebrities such as Winnie Harlow, who featured in the twenty-first cycle of the US hit TV show *America's Next Top Model* in 2014. I had even heard of it in my own family, with stories about how my grandmother had vitiligo but was not particularly disturbed by it because it "couldn't really be seen" on her pale (white) skin.

As I began to learn more about vitiligo I began to realise the value that it might have as a case study in my research. The relative invisibility and visibility of AKU and vitiligo respectively would mean that drawing a comparison between the two would allow me to explore the role of disease visibility in the everyday lives of people with chronic diseases more broadly. Because

both diseases are chronic and progressive I was interested to see if patients expressed similar concerns about the future in terms of how they will one day *look* and *feel*, and how that might affect their interactions with others. I was also interested to see if patients shaped their future dreams and aspirations around how they thought their symptoms might progress in the future. After I decided to use these two diseases as case studies to discuss social visibility and chronic health conditions in greater depth I framed my research questions in the following way:

1. In what ways and/ or to what extent do people with AKU or vitiligo experience feelings of social (in)visibility because of their disease?
2. How do participants from both disease groups manage their everyday experiences of social (in)visibility?
3. How does the relative (in)visibility of their symptoms affect their everyday experiences of living with their disease?

From there I formed a research design that would allow me to address these questions by interviewing patients about their experiences and by observing them at two international patient conferences, both in the US and in the UK.

Data Collection

When I began this project I did so knowing that I had the full support of the AKU Society (UK), who said that they would assist me in my initial process of contacting and recruiting patients. Because this charity is UK based, most of the patients that they were in regular contact with were from the UK or EU, which meant that they had to reach out to other researchers who knew of US-based AKU patients. In the initial stages of my study one of the team members who was in charge of patient outreach created a blog post on a patient website asking for any African-American patients to contact me (needless to say no one responded to this post). Another team member then reached out to all of the US-based patients that they knew of (approximately 35), of which 18 responded and expressed an interest in participating in my research. I began interviewing these patients in September 2016 via Skype, roughly 4 months before I was due to begin my fieldwork in the US.

Unlike my search for AKU patients, I did not begin my search for people with vitiligo with a network already in place to support me. As a result, I had to contact potential participants directly and, knowing that there was a large online vitiligo community that primarily formed in groups on Facebook and Instagram, I chose to do so through social media. I looked on Facebook at open vitiligo support group pages and identified the most vocal and consistent members. I chose to contact these members directly because their statements and messages of support typically showed both a willingness and an eagerness to communicate their

experiences to others. I sent these people private messages outlining the details of my study and my interest in interviewing them. I also related the anticipated length of the interview, which was roughly 50-60 minutes. I initially chose to contact around 5 potential participants at a time in order to manage the number of responses that I hoped I would receive. A number of members chose not to respond to my initial message and I did not pursue them further as I did not want to make them feel pressured in any way to participate in my study, or indeed discourage them from joining in the conversations that were happening in any of the groups.

The first person to respond to my invitation was Linda, who did so with a great deal of enthusiasm. She immediately detailed the work that she had been doing to set up a vitiligo support group in her local community following her diagnosis, as well as other vitiligo advocacy work that she was involved in. We arranged to speak via Skype, and had our initial interview in August 2016. After we got to know each other further (I interviewed Linda a total of 4 times) she agreed to put me in contact with some of the other members of her support group. She also put me in touch with the founder of a vitiligo support group in Washington DC, who I would later interview during my fieldwork. From there I was able to carry out 3 additional interviews, all of which were also conducted over Skype. Each of these participants then put me in touch with friends of theirs who also had vitiligo and were keen to participate in my research. In a similar way, after the AKU society put me in touch with US-based AKU patients who agreed to participate in my study, I was able to reach out to a few other patients through them. I was introduced to one patient, Claire, through Luke who was introduced to me through the AKU Society. Both patients maintained a steady online friendship, and regularly contacted each other with updates about how they were managing their AKU symptoms and any useful advice that they had received from doctors.

By the time I left for fieldwork in January 2017 I had conducted 6 interviews with participants from both disease groups. I chose Washington DC as my field site for 3 reasons: firstly, because it is within an easy distance from the NIH where the leading US-based AKU medical specialists are located. Secondly, because one of the leading dermatology departments at that time that specialised in vitiligo was based in Howard University Hospital, which is in Washington, DC. I applied to the sociology department at Howard to use their facilities during my fieldwork and they approved this request. Knowing that the sociology department at Howard had medical sociologists who were affiliated with the hospital, I hoped that I might be able to gain access to doctors who specialised in vitiligo. However, I was unable to gain access to any of the medical specialists that I sought to interview. Despite sending numerous requests to their secretaries, both in person and via email, none responded to my invitation for an interview. The third reason why I chose Washington DC as my primary field site was because I already knew of an active vitiligo support group in the city and had been in regular correspondence with its organiser. The organiser assured me that I would be able to regularly attend their support-group meetings, and that he was happy to facilitate my initial introductions to the group members.

Because AKU is a rare disease patients are dispersed across the US. Knowing this, when I was finalising my field site I knew that I would not be able to choose an area that had a high concentration of patients. However, because vitiligo is more common (affecting roughly 1-2 million people in the US) (Silverberg et al. 2014) I thought it fairly likely that I would come across people with this disease if I chose to locate my field work in any area with a dense population. Because Washington DC regularly sees an influx of tourists who visit the city for its museums and other attractions, I thought it likely that I would come across people with vitiligo on a relatively frequent basis. For this reason I often frequented coffee shops, restaurants and parks in parts of the city that were particularly popular amongst tourists. Initially I anticipated that this might be a good way of recruiting participants for my study if, for some reason, I was unable to access them through the local support group. I also anticipated that the people that I would be interacting with who had vitiligo would likely be tourists from a range of areas across the US, and thus would provide me with a diverse set of responses. However, whilst I did come across a number of people who had noticeable signs of vitiligo I found that I was reluctant to approach them in public. Because they were often in transit (i.e. moving from one location to another), it was difficult to introduce myself to them, which prevented me from inviting them to participate in my study. In addition, I was concerned that by approaching them I would call attention to their condition and, potentially, make them more self-conscious about it than they perhaps already were.[11]

I chose to use qualitative methods because of my project's focus on the everyday lived experiences of people from both disease groups, and the extent to which those experiences shaped their feelings of social (in)visibility. I chose to use semi-structured in-depth interviews in particular because this method allowed for the discussion that I had with participants to be shaped in accordance with each individual's personal experiences. Because I did not know what those experiences consisted of or the ways in which those experiences might differ between people from within the same disease group, this seemed like a useful way to ask specific questions that allowed me to address my research questions whilst allowing for any nuances that might come from different patient experiences. In total, I conducted semi-structured in-depth interviews with 34 patients from both disease groups. 18 participants had AKU, and 16 had vitiligo. The interviews lasted between 50 minutes and 3 hours and 30 minutes, with an average time of 1 hour and 15 minutes. Of the participants with AKU, 9 were female and 9 were male. All but one was white, and most came from high social and/ or economic backgrounds. Three of them had second homes, and all had some form of medical insurance.[12] In terms of occupation, several of the AKU patients were or had been lawyers, engineers and independent business owners. Because of their age and the fact that their

[11] I did, once, sit next to a man with vitiligo in a coffee shop near my apartment and I told him of my interest in his condition and expressed a wish to interview him about it. He seemed eager to talk but was reluctant to discuss it in a public place and, instead, invited me to his home. I was uncomfortable with this arrangement and, therefore, declined the interview.

[12] Most had private health insurance through their employers, and at least two were the recipients of federally funded programs (including Medicare and Medicaid).

disease symptoms had significantly progressed, most of them had either retired or semi-retired at the time of the interview. Of the participants with vitiligo, 11 were female and 5 were male. 4 were white, and 12 self-identified as either black or African-American. Whilst several had a significant amount of social capital because of their role as activists within their community, most did not have a great deal of economic capital. This was made known to me by their comments on the high cost of effective vitiligo treatments, and the ways in which they were barred from these treatments because their medical insurers did not cover the cost of them and they did not have the financial means to pay for them. The occupations of these participants varied widely; some had "professional" occupations (i.e. councillors, teachers and medical assistants), whilst others worked as taxi drivers, warehouse operators and fast food waiters/ waitresses. 3 of the participants were unemployed at the time of the interview, 2 because of unrelated health problems, and 1 because she was heavily pregnant with her first child. All of the participants in this study were given pseudonyms to ensure their anonymity, and each participant's location was generalised so that their responses could not be traced back to them.[13].

I framed the interview questions in a way that would allow me to address my research questions without leading the participants in any way. I began each interview by asking when the participant was diagnosed with their condition, and then asked how they felt immediately after receiving the diagnosis. I then asked them if they had undergone any treatments for their disease and, if so, what their experiences of those treatments were. I then asked questions that specifically related to potential variables between patients in terms of race, class, age, gender etc. (i.e. "do you think that age affects your ability to deal with this disease?" "Do you think that different racial groups experience this disease in different ways?"). From there I would ask questions related to staring and experiences of stigmatisation whilst in public spaces (i.e. "Would you say that people often stare at you and, if so, how do you deal with this?" and "have you ever tried to hide the fact that you have your disease from other people? If so, why?"). I would then ask questions that directly relate to lifestyle adjustments and disease management practices (i.e. "Have you done anything to change your diet because of your disease?" "Have you done anything to change your lifestyle in general because of your disease?"). Because these interviews were semi-structured I used these set questions as a guide and often found that, in their responses, participants answered several questions at once. I ended each interview by asking the question "what do you want other people to know about your experiences in living with this disease?" before asking them if they had any questions for me.

Whilst I conducted several of these interviews face-to-face (both in participants' homes and in communal areas such as restaurants and cafes) most of the interviews took place online through mediums including Skype, FaceTime and Facebook Messenger. Of the AKU participants in my study, 4 were conducted face-to-face and 14 were conducted online. Of the

[13] For example, if a participant named the town that they resided in I would either refer to the state that they were from or fabricate a town in that state.

vitiligo participants, 2 were conducted face-to-face and 14 were conducted online. Before I began interviewing I anticipated that conducting most of my interviews online would, potentially, limit the amount of data that participants shared with me because it might prevent us from forming a "trusting" relationship with each other. I was also concerned that it might limit my overall understanding of their disease experience by preventing me from seeing any mobility issues that AKU patients might have, as well as the full extent of the vitiligo participant's depigmentation. I was, therefore, pleasantly surprised to find that these interviews yielded a significant amount of data that I might not have otherwise had access to if the interviews were carried out face-to-face. Participants seemed confident when discussing symptoms that they might otherwise have felt embarrassed talking about in face-to-face conversations, such as having dark sweat and depigmented areas of skin on their genitals. One AKU patient actually held her sweat-stained shirt up to the camera so that I could see what her sweat looked like. In addition, when it came to transcribing these interviews, I was able to record these incidents in relation to what was discussed, which undoubtedly added greater depth to my analysis later on.

After each interview I wrote detailed notes of how I thought the interview had gone, as well as any tensions that might have arisen and any notable or different responses that participants might have given to the questions that I asked. I then elaborated on why these differences struck me as particularly noteworthy and considered any broader avenues of thought that might inform my research questions. As the interviews continued my interview questions shifted slightly in accordance with the responses that participants gave. Consistent with the grounded theory approach, I shaped my questions in order to gain further insights into areas that I had not previously considered (Charmaz 2014). In addition to these semi-structured interviews, I carried out 2 short ethnographies lasting between 2 and 3 days at international patient workshops and conferences both in the UK and the US. The international AKU patient workshop was held in Liverpool, UK, in April 2018 and was attended by roughly 80 patients, some of whom were the US patients that I had interviewed online. I was invited to speak at this event and present my research findings to the patient attendees. This workshop provided me with the opportunity to interact with patients from outside of the demographic that I was focusing on (the US) and allowed me to see how patients interact with each other and how they discuss disease-related concerns. In addition, I attended a three-day international vitiligo patient conference in Detroit, Michigan in June, 2017. This conference was attended by a number of the people that I had interviewed, as well as advocates that I was familiar with because of their social media following and leading medical specialists. All had travelled from various locations across the US, as well as from neighbouring countries such as Puerto Rico. I was the only attendee who had travelled from Europe, and I received a great deal of positive attention for doing so. Attending this conference allowed me to interact with several of the participants that I had, up until that point, only been able to speak with online. In addition, it gave me the opportunity to further develop my network of participants. I was able to recruit

several participants for my study at this conference, and was invited to join a number of closed social media patient advocacy and support groups.

Since returning from my fieldwork, I have regularly remained in contact with several of the participants that I interviewed from both disease groups via social media, and have kept up-to-date with their day-to-day struggles and accomplishments in managing their diseases through a number of social media sites, such as Facebook and YouTube. After each interview, I made a point of not actively befriending any of my participants on social media. I was concerned that this might overwhelm them or make them feel obliged to speak with me in further detail about their experiences when they, perhaps, did not want to. However, several of them independently reached out to me and expressed an interest in remaining in contact with me and staying up-to-date with my research. After their interviews, a few participants from both disease groups sent me documents that they had discussed during the interview. These participants often said that they felt that it was important for me to see these documents in order to understand their disease experience more fully. Two AKU patients sent me the photographs of their damaged joints and bone cartilage that they had requested from their doctors during surgery.[14] Another AKU patient sent a diary excerpt that he wrote during a three-day check up at the NIH. One vitiligo participant sent me some of the poetry that he had written and previously performed at spoken word poetry events at his local college. These poems shed light on intimate areas of his personal life that he touched on during the interview but did not discuss in detail. Another vitiligo participant sent photographs of her wearing some of the advocacy t-shirts and badges that she made to raise money for her local support group.

In addition to gaining further insights into the day-to-day lives of participants through social media, I was granted access as a researcher to the *PatientsLikeMe* online network by the website's administrators. This network provides a platform for patients with a range of conditions to share their experiences with other patients and learn of any new clinical trials and treatment options as they become available. I immediately noticed that one of the AKU participants in my study was a member, and that she posted in the group on a regular basis. During the interview this participant discussed her role as an online advocate and mentor for those who had recently been diagnosed with AKU, and frequently commented on the ways in which this helped her to "find a purpose" in her diagnosis. Because I had, up until that point, only interacted with patients individually, this network allowed me to see how patients forged connections with each other through their patient community. It also helped me to identify the primary concerns that patients from within this group collectively held. Unlike AKU patients, people with vitiligo tend to form online communities through social media websites such as Facebook, Instagram and YouTube. Because vitiligo is more common, it is easier for

[14] Note that many AKU patients requested these photographs from their doctors so that they could visualize their disease's progression and see the damage that the disease was causing to their bones and joint cartilage.

people with this condition to connect with others who also have it online. With the exception of two participants, I contacted all of the people that I spoke to with vitiligo either through social media or through other people that had already agreed to be interviewed. One of these exceptions, Jessica, was made known to me through a blog that she started that aimed to relate the story of "girls and young women" with vitiligo. I contacted Jessica through this blog and she agreed to be interviewed. I came across the other exception, Lauren, when I found an online photography exhibition that she ran showcasing the "beauty" and "uniqueness" of people with vitiligo. I contacted her through her website and she also agreed to be interviewed. I personally transcribed all of the interviews that I conducted verbatim.

Initial Stages of Data Analysis

Throughout the research process I used a grounded theory approach to collect, analyse, synthesise and, eventually, write up my data. When outlining what grounded theory is and how it is used, Kathy Charmaz argues that it is a methodology that aims to "bring an open mind to what is happening" in empirical data "so that we can learn about the worlds and people we study" from that data (Charmaz 2014, p.3). It encourages researchers to begin their research project with as few pre-conceived ideas about what their data will reveal as possible, whilst acknowledging that the researcher will likely have a rough idea of the direction that the research *could* go in beforehand (Charmaz 2014). In addition, it suggests that researchers should collect their data using any qualitative methods that they deem appropriate and well-suited to their particular research topic (i.e. semi-structured interviews). After they have collected their data, researchers should then begin the process of coding which, according to Charmaz's interpretation of grounded theory, consists of two key steps:

1) [A]n initial phase involving naming each word, line or segment of data
2) [A] focused, selective phase that uses the most significant or frequent initial codes to sort, synthesise, integrate, and organise large amounts of data.

(Charmaz 2014, p.113)

First, the researcher begins by open coding the text that contains the data they have collected (i.e. an interview transcript). Then the researcher revisits that data and selectively codes it in accordance with any recurrent codes that might guide a potential research direction. When I initially coded my research I went through each interview transcript and considered the data line-by-line without looking for any correlations between individual participants or disease groups. Then, when I later revisited this data, I focus coded in order to outline any emerging themes. Because my study is comparative, I chose to do this first *within* individual disease groups and then *between* these disease groups. In other words, I initially sought out correlations between my codes within each of the disease groups separately and then

compared the two sets of "selective" codes with each other. This allowed me to point to any specificities that had emerged within each group that did not necessarily correlate with what was being said in the other group. I chose to do this primarily for reasons related to experiences of symptoms that were particular to each disease (i.e. dark urine and depigmented skin). In addition, it allowed me to locate any emerging crossover codes that came from conversations with participants from both disease groups (i.e. physical and emotional pain, what it meant to feel "ill," experiences of stigma etc.). These crossover codes then informed the subsequent memos and free-writes that I wrote, which I will discuss in my section on data synthesis.

Whilst I was compiling a list of these crossover codes I regularly used the grounded theory method of "clustering" to help me to further explicate them. Using a large sketchpad, I would write down one of my selective codes and think about the broader implications of that code and how it operated in similar or dissimilar ways between both disease groups. These codes would typically be short (roughly 1-6 words) and would function as a springboard, allowing me to think about it in relation to specific experiences that were discussed in the interviews as well as related themes and ideas.

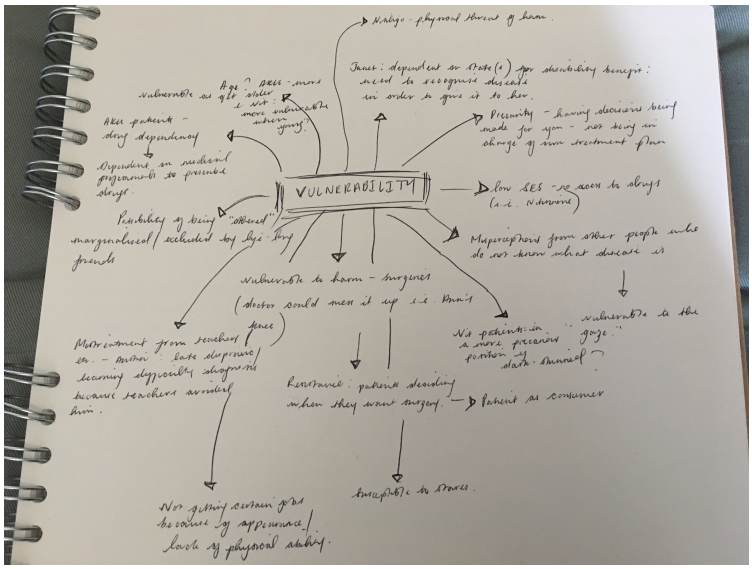

Figure 1.

This is an example of one of the selective codes that I used: "vulnerability." Some of the broader themes that emerged from this code included: precarity (i.e. not being in charge of one's own treatment plan), resistance (i.e. attempts to reject feelings and/ or position of vulnerability), vulnerability to harm (i.e. through surgery), mistreatment from those in positions of "authority" (such as doctors and other medical staff) etc. Some of the specific examples that came from my empirical data included: Janet (AKU) and her financial need for disability benefits, Austin (vitiligo) and the mistreatment that he suffered at the hands of

teachers who, because of his vitiligo, did not want to teach him, and Amy (AKU) who argued that her doctor caused further damage to her knee during surgery.

After I finished drawing these codes and extrapolating data from those drawings I wrote a series of initial free writes to further unpack what those codes and the ideas that came from them meant in relation to some of the broader issues that participants discussed in terms of their day-to-day experiences. These free writes consisted of a number of flow charts that showed the sequencing of processes that described how patients were relating their feelings of social (in)visibility. The purpose of these flow charts was to map emerging trends alongside theoretical underpinnings that explore social (in)visibility in greater detail.

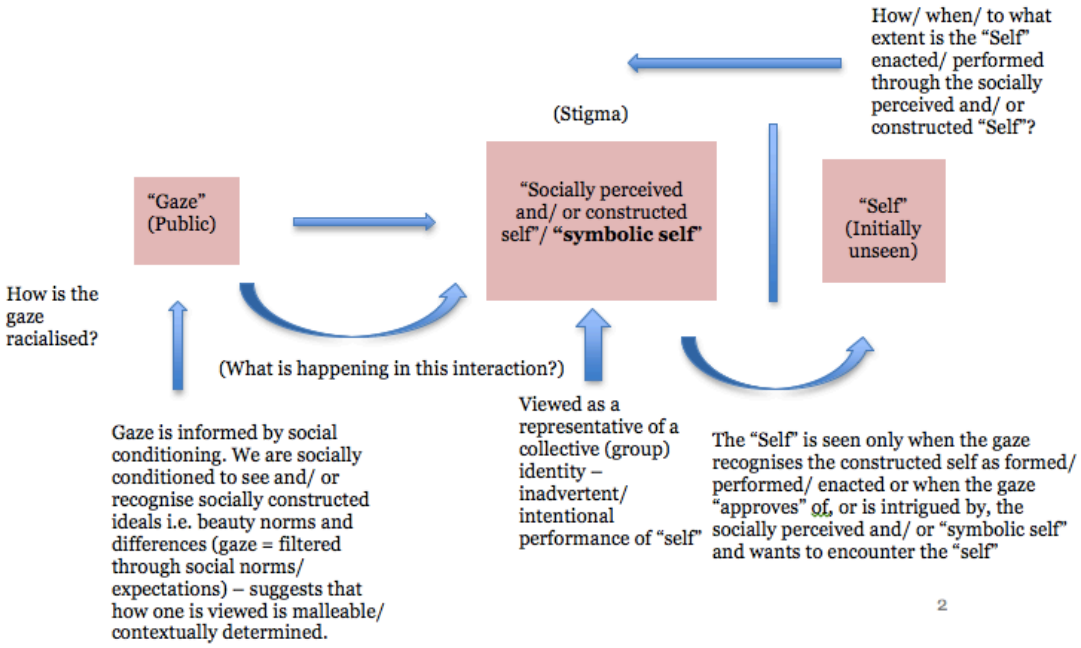

Figure 2

This flow chart came from the selective code "(in)visible disease 'patient' as medical spectacle." By using this code as a starting point, this flow chart allowed me to think more critically about the correlations between disease visibility and social visibility. By drawing a distinction between the two separate "selves" that participants often discussed (the "socially perceived/ constructed/ symbolic self" that they show to others and the "unseen self" that they initially keep to themselves), I constructed a framework that allowed me to think about this aspect of their disease experience (and the feelings that often emerged from that experience) more fully. I then began to think about the ways in which this framework might inform some of the other selective codes that came from my data (i.e. how stress is communicated through the body, affective responses to different stages of disease (in)visibility, visualising chronic pain etc.).

Data Synthesis

After I collected and coded all of my data I began to further develop my thoughts on the focused codes that came up as I was analysing both diseases. Some of these overlapping codes included: concerns about passing on the disease to children, the importance of looking "healthy" in social environments, the incommunicability of pain, bodily responses to physical and emotional trauma, the importance of hope etc. I developed these codes through a series of memos and free writes. The free writes were particularly useful as they allowed me to develop my initial thoughts alongside some of the key ideas that emerged from the social theory that I was reading. In line with grounded theory, I thought it important to first ensure that I analysed my data by open coding, close coding, writing memos and free writes etc. before applying theoretical approaches that might help me to better understand my findings (Dickson-Swift et al. 2007; Charmaz 2014). I also thought it important to consider my data by itself and to develop themes independently from social theory in order to ensure that my data was shaping my use of social theory rather than social theory shaping my data.

Typically, I would use one of my focused codes as a starting point/ heading and then I would write a free write about that code. I would start by considering what the code meant to each disease group, and then conclude by considering how the responses that each disease group gave overlapped to form an understanding of what that code means in relation to my project. As an example, below I have included an excerpt from a free write that I wrote shortly after I left my field site. The code that I used as a starting point for this free write was called "the importance of photography:"[15]

> There is a trend at the moment for people who have vitiligo to publically announce and assert their "comfort in their own skin" by taking selfies and attaching phrases such as "loving the skin that I'm in" to these images. These people are assumed by the wider vitiligo community to have "made it" in their "journey" towards self-acceptance. Because vitiligo is a chronic condition this step is often viewed as one that is necessary; there is no cure so if the person with vitiligo doesn't accept themselves in their altered state they are destined to live a life of misery that is driven by self-hatred. There seems to be a binary that does not allow any middle ground for *relative* acceptance – it is believed that people either love their vitiligo or hate it. In producing selfies and public posts affirming their acceptance, "patients" are understood to "love it" and are praised for this by the wider vitiligo community. Those who do not publically announce that they love it are subject to chastisement. One of the ways in which people can do this is by openly talking about make up use/ spray tanning. Numerous AKU

[15] I later used this code as a starting point for a journal article that I wrote called "Embodied Responses to Medical Photography." At the time of writing it is under review by *Social Theory & Health*.

> patients opt to have photographs taken of their joints in order to map the progression of their ochronosis. These photographs are often kept by the patient for his or her own records and are disseminated to interested medical parties for research purposes. They are a way for patients to assist in the research process, and in this way enable the patient to demonstrate their autonomy *as patients*. Although they are subject to the clinical gaze/ the medical observer (i.e. the surgeon) they are included in the production of knowledge. Vitiligo "patients" also often express similar motivations, saying that they want to "help doctors" by showing them how "bad"/ extensive their vitiligo is.
>
> (Excerpt from free write – 22.04.2017)

From this free write I wrote another that teased out some of the ways in which participants use visual representations of their bodies (i.e. photographs) to articulate their positionality as "patients" within medical discussions that centre biomedical understandings of their diseases.

From these free writes I then began to think about particular themes and topics that relate to my overall research questions, and the different ways in which my selected codes and memos informed those questions. Over a period of roughly 6 months I committed to writing at least one free write each morning for 15 minutes. At this time I was reading works of social theory to see what was useful for my research, and these free writes helped me to ground this work within findings from my empirical data. As I continued to read social theory I revisited my memos, original free writes, interview transcripts and field notes in order to make sure that I did not stray far from my data in the initial conclusions that I was making. My next step was to synthesis my data and theoretical framework in order to write my findings in a way that was coherent and relatable. For my second-year report I wrote a detailed summation of what I understood to be the important gender dynamics at play within both disease groups in relation to concerns about reproduction, fertility and child rearing. Whilst this report did not go on to form a chapter in my thesis, it did inform and contribute to my understanding of other focused codes that later came up when I revisited my interview transcripts, i.e. difficulties in dealing with stress and emotional trauma, concerns about disease progression etc.

After my initial two – step coding process, I re-visited each interview at least once and completed this process again. With some of the more detailed interviews I did this 3 times, whilst simultaneously re-reading my notes, memos and free writes. I did this for 2 reasons: firstly, to ensure that I had not overlooked any crucial points of interest during my first few readings, and secondly in order to see if anything new emerged from this data after I had spent time reading other interviews. This stage of my data synthesis reflected my attempt to

view the interview transcripts collectively, and to recognise any emerging patterns that might come out of this. After I spent time re-visiting my data and pointing to emerging themes I then used those themes as starting points for possible journal articles and conference papers in order to further explore these ideas.

I've written four empirical chapters based on what I understood to be the four most prominent overlapping themes between both disease groups in relation to the question of social (in)visibility. These themes include: stigma, passing, pain and the idea of being "personally responsible" for having visible disease symptoms. It is important to note that my pre-conceived interest in all of these topics undoubtedly informed my decision to pursue them further in this research project. As noted by Charmaz, "[w]hat you see in your data relies in part upon your prior perspectives" (Charmaz 2014, p.132), therefore what I already knew about social invisibility based on the work that I had previously done on the topic undoubtedly informed my understanding and interpretation of these emerging themes. However, I was careful throughout the research project not to let my preconceived ideas about what I thought "I knew" shape what my empirical data suggested. Following Charmaz's advice, "[r]ather than seeing [my] perspectives as truth" I tried to see them as "representing one view among many" (Charmaz 2014, p.132).

My own positionality and subjectivity

As a researcher with neither of the diseases that I chose to study, when I began this research I anticipated feeling like an outsider when talking to participants from both disease groups. When I began my initial search for AKU patients through the AKU Society I was concerned that my outsider status might cause patients not to trust me, and that this distrust might make them reluctant to participate in my research. Indeed, there were several US-based patients that the AKU Society contacted who did not want to participate in my research or receive any further contact from me. Yet, on the whole, I found that the AKU patients who agreed to participate in my research did so with a great deal of enthusiasm. Many expressed their excitement about the fact that I had chosen their particular disease as one of my case studies, with some conveying feelings of gratitude that I had shown an interest in them and their disease when a number of researchers chose to focus on diseases that were more well-known and/ or that directly increased rates of morbidity (i.e. cancer). This largely positive reaction was, I believe, partly due to the fact that I was introduced to them through the AKU Society; a charity that all of them were familiar with.[16]

[16] Dr. Smith put me in touch with a number of AKU patients in the Washington DC area and personally recommended me to them based on our previous interactions.

As previously stated, I initially contacted potential vitiligo participants individually through various social media websites. Because I was not introduced to them through a medium like I was with the AKU patients, they (generally speaking) did not respond to me with the same level of enthusiasm and/ or excitement. A few people responded to my request for an interview with scepticism, requiring further information about my study before consenting, and many did not respond at all. At the time of the interview, all of the people with vitiligo that I spoke with had learned to cope with the condition and the changes that it had made to their appearance. All discussed feeling ostracised and/ or shunned on numerous occasions after their symptoms began, and all claimed that they had experienced feelings of self-hatred at some point over the course of their disease. Yet, at the time of the interview, none of these participants related feeling either of these things. Indeed, many claimed that they had not experienced those feelings for some time. Most vitiligo participants conceptualised their disease experience in relation to their "vitiligo journey," which was a term that they used to detail the ups and downs that they faced in dealing with the changes that their vitiligo had made and/ or was making to their appearance, and the negative reactions that they received from other people as a result.

Despite my efforts to recruit participants who were still dealing with issues related to self-acceptance and self-esteem because of their vitiligo, I was unsuccessful in doing so. I think it likely that this was because these people might have felt uncomfortable relating personal issues that they were still dealing with to a stranger. The emotional labour involved in talking to a person that they did not know about those experiences might have been too difficult for many to handle, particularly when that stranger was a researcher who did not have the condition and, therefore, could not fully know or sympathise with their difficulties in coming to terms with it. This is not a problem that I encountered with AKU patients. On the whole, patients from this disease group were open and ready to discuss their experiences despite the fact that, at the time of the interview, they often felt the effects of their disease symptoms (i.e. chronic pain). This is not to say that these patients did not find it difficult to relate their lived experiences to me. When discussing their chronic pain in particular patients would often convey feelings of frustration at not being able to effectively relate those experiences to me as someone who did not also share them. However, AKU patients were largely unafraid of relating the emotional difficulties that they continued to face in relation to their everyday symptoms, and routinely opened up about those experiences without being prompted.

Despite the willingness and candour that people from both disease groups showed when relating their struggles in coming to terms with their condition and their everyday experiences of dealing with it, I was continuously made aware of my position as an outsider throughout the interview process. This was not because participants directly called attention to my outsider status. Indeed, many made a great deal of effort to make me feel included in our conversations by highlighting our similarities in terms of hobbies, education, wider interests etc. Rather, it was because as I was listening to their stories I could not help but reflect on my

own "good health" and the everyday benefits that that afforded me.[17]During the interviews I routinely reflected on the ways in which I had, up until that point, taken my "good health" for granted. As I will later discuss, when asked what it meant to "look healthy" participants from both disease groups would often say that I look healthy and, therefore, "looking healthy" meant looking like me. Interestingly, although patients often conceptualised "good health" in relation to something that their disease symptoms prohibited them from doing (i.e. walking for significant lengths of time, going out in public and not being stared at etc.), when they used me as a model for what "looking healthy" meant to them they were united in claiming that it meant having "nice" skin, being "slim," being "active," being "social" etc.

As the AKU interviews progressed and participants continued to use me as an example of what being healthy "looked like," I became increasingly aware of the ways in which I was not prevented from participating in activities because of any mobility restraints and/ or fatigue that I experienced. Similarly, as I was interviewing people with vitiligo, I began to consider my own appearance in ways that I had not previously done, particularly in relation to how it likely influenced my interactions with other people. Numerous scholars have detailed having similar reflexive responses to the stories that their participants shared during interviews, particularly when those stories centred experiences of disease or prolonged periods of illness. Writing about her experiences interviewing women with breast cancer, Kathleen Rager notes that during the 15 months that she was collecting data she experienced feelings of "sickness" in response to their stories. During this time, her diary entries featured accounts of "experiencing symptoms, both real and psychosomatic, that included digestive problems; abdominal, back, and breast pain; skin problems, and sleeplessness – especially during the time of the interviews" (Rager 2005, p.23). Upon further reflection, she notes that what she was experiencing was "directly related to being immersed in the process of collecting heart breaking data and engaging both intellectually and emotionally with [her] participants" (Rager 2005, p.23). In a similar way, in their book *Emotions and Fieldwork*, Sheryll Kleinman and Martha Coop argue that social scientists who use qualitative methods that require them to directly engage with others need to acknowledge their own vulnerability within the field, and discuss the ways in which those feelings of vulnerability inform their research. Qualitative researchers, they argue, "should recognise the constructed nature of their fieldnotes, commentary, and ethnographic accounts" in order to understand how their data is produced (Kleinman & Copp 1993, p.55).

According to both authors, when researchers enter the field we do so with a number of pre-conceived ideas about human relations that directly inform our initial understandings of that field. Moreover, how we view the field and what we gain from the data that we collect whilst in the field is largely influenced by our own pre-conceived interests and ideas that, ordinarily, stem from our own lived experiences. My own experiences as a bi-racial woman growing up in

[17] By "my own good health" I am specifically referring to the fact that, whilst interviewing, I did not have any physical or mental health issues that affected my day-to-day life.

a predominantly white town informed my interest in questions centring social visibility and what it means to look "different" from most of the people with whom you come into contact with on an everyday basis. My interest in passing stems from my personal experiences of feeling accepted and/ or being viewed as "acceptable" in certain spaces because of the way that I speak, dress and behave.[18] Whilst unrelated to the experiences of illness and disease that participants discussed during their interviews, both experiences informed the research direction that I chose to take in my PhD and, therefore, were central to my research process.

In addition to calling attention to my own "health" in comparison to theirs, participants would often ask me whether their responses differed from the responses that other participants gave to the same question. Many interrupted themselves whilst speaking by asking the question "is this normal?" when giving a particularly emotive response to what they viewed as an "ordinary" question. During her interview one participant began to cry after discussing a fight that she had had with her brother about her inability to regularly care for their mother because of her chronic pain and fatigue. After she started crying she repeatedly asked me to excuse her for responding in this way, despite my assurances that no apology was necessary and that she should take as much time as she needed when answering questions. She also repeatedly asked whether it was "normal" to respond that way, and if other participants had done the same when relating particularly difficult and/ or emotional incidents.

During their interviews participants from both disease groups would also often ask me how their health fared when compared to other people who had their disease. Viewing me as an "expert" on their condition, they would often ask whether the other people that I had spoken to had progressed at similar rates to them, and/ or if they used the same disease management strategies in order to cope. When discussing the fact that she had yet to have any joint replacement surgeries, one AKU patient, Natasha, asked me whether or not I thought she might need them one day. Although I told her that I was not a medical expert and, therefore, could not be sure of the likelihood of her needing surgery in the future, she continued to view me as an expert throughout the interview and routinely asked me other disease related questions that required medical expertise. Another AKU patient pointed to the joints that were causing him the most pain and asked me to briefly examine them to see if they would likely need replacing in the near future. Participants with vitiligo often asked me if other people that I'd spoken with who had the condition had experienced the same level of depigmentation in specific areas. One participant, Jennifer, enquired whether any other participants had reported having vitiligo on their genitals, and whether this caused them any emotional disturbance. Another participant asked if others also had seemingly unrelated

[18] By this I refer to the fact that I have never felt "othered" or "marginalised" because of the way that I speak, dress, or behave in any of the social environments that I have thus far resided in.

autoimmune diseases such as lupus and fibromyalgia, which they believed were associated with vitiligo.[19]

By positioning me as a medical expert, participants often unintentionally shaped our discussion so that, at times, it mirrored a medical consultation. It was clear that some of them viewed our interview as an opportunity to seek medical advice and stay up to date with the latest clinical trials and drug treatments that were being offered. This was particularly the case with AKU patients, many of who did not know of any other people with AKU and were not actively involved in any of the clinical trials that were being carried out by the NIH. After their interviews participants from both disease groups would often thank me for "selecting them" for my study and for choosing their particular disease as a case study. One AKU patient claimed that my decision to study this disease showed that I have a "big heart," and another said that he thought it "very cool" that I had chosen it because it meant that others were more likely to know about the disease. In a similar way, numerous vitiligo participants expressed enthusiasm for my research because they believed that it would help "spread the message" and generate awareness about their condition. On several occasions participants from both disease groups thanked me for offering them what they viewed as a form of "therapy." The interview, many argued, gave them the opportunity to express how they were feeling in relation to their everyday symptoms, interactions and experiences. As noted by one participant: "it's been a while since I've talked about this to anybody … just speaking things that I feel on the inside. It wasn't just like an interview that was meant to be used for something for you, this was actually something that for a while I've needed to do so it was actually nice." Because they often tried to hide or downplay any negative feelings that they had when they were with their family and or/ close friends, these participants rarely got the opportunity to voice them. They claimed that discussing them with me gave them the opportunity to vent their frustrations in ways that they had not previously been able to.

Narrative accounts of "illness" often comment on the need that chronic disease patients feel to discuss their experiences at length with others (Bair & Cayleff 1993; Lorde 2017; Khakpour 2018). This need often comes from a lack of understanding from disinterested and/ or unsympathetic doctors who only see the patient in relation to their disease (Conrad 2007; Lupton 1997; Spence 1986). As noted by Havi Carel in her reflections on her experiences of living with LAM (a debilitating lung condition that frequently leaves the person with it short of breath): "I quickly learned that when doctors ask, 'How are you?' they mean, 'How is your body?' and that when an X-Ray of my lungs is up on the screen and several doctors stand around it discussing my 'case,' they will not include me in the discussion, even if I am standing right there. They will not want to know how my life has changed because of my illness, or how they could make it easier for me" (Carel 2019, p.50). Numerous AKU and

[19] During their interviews numerous vitiligo participants discussed what they perceived to be a correlation between this disease and other auto-immune diseases such as lupus and fibromyalgia. Whilst many medical specialists have argued that having an autoimmune disease increases the likelihood of that person later developing vitiligo, at the time of writing this has not yet been proven.

vitiligo participants expressed similar sentiments during their interviews, with many claiming that our interview was the first time that they felt "heard" as people who were living with their conditions. Viewing themselves as disease "experts," these participants would often discuss how their lived experiences should be central to any medical discussions about their disease. As noted by one participant: "the disease wouldn't be anything without patients so medical doctors should listen to us and take what we have to say seriously."

As I discussed at the beginning of this chapter, when I initially began this project I did so with the intention of centring questions of race and racism in relation to how people with AKU coped with their everyday experiences of living with this disease and its symptoms. As a black woman, I did not anticipate that black patients would feel hesitant when opening up to me about their experiences of racism. Although I knew that many might feel frustrated when discussing their experiences of pain and chronic fatigue to someone who did not feel either of these symptoms, I was confident that my subjective position as someone who is also racialised would invite their trust and candour when discussing issues related to race and racism. In this way I felt that I held an "insider status" that made me privy to certain types of knowledge, whilst similarly remaining an "outsider" because I did not have their particular disease (Merton 1978; Naples 1996; Couture & Maticka-tyndale 2012; Song & Parker 1995).

As previously noted, I was able to interview a range of people with vitiligo from different racial groups, which helped me to gain an understanding of the different ways in which those groups are affected by it. Because the disease is significantly more visible on people of colour than it is on white people, most participants (black and white) concluded that it was likely to be more difficult for people of colour to emotionally deal with. When I asked black participants to elaborate further, they would often go into detail about specific instances of marginalisation and/ or exclusion that they had experienced from white and black people because of their vitiligo. Several participants commented on how black people tend to "judge" them more and how black people are, generally speaking, more "ignorant" than white onlookers about what their disease is and what it means for them in relation to their health. As noted by one black participant: "I would say in the black culture, speaking from my perspective, it was very tough you know because sometimes you know black people have said some of the rudest comments I've ever heard in my life! Where you know you might see a few stares from white people … black people will be very rude and [will] make obnoxious comments a lot." Whilst I was interviewing these participants I got the impression that they would not have demonstrated the same level of candour about these types of intra-racial prejudices had I not also been black. This impression stemmed from their often repeated use of the phrase "you know" when relating these types of prejudices.

In addition to my position as a racial "insider," I believe that my position as a female researcher also helped me to gain the confidence of many participants (particularly those who self-identified as women) during their interviews. I got the impression that many of them

would not have shared detailed personal information with me if I had not also been a woman, such as their concerns about depigmented areas of skin on their genitals or their worries about producing dark breast milk if they one day became pregnant.[20] Often speaking in hushed tones, they would relate these concerns by tying them specifically to their positionality as women who felt pressured to "look good" and be "good mothers" by breast-feeding their children in the "correct" way.[21] In doing so, they would often purposefully invoke a frame of reference that would include generalised experiences of being a woman that they thought I might be able to relate to.

When interviewing male participants I often found that several responded flirtatiously to questions that I asked them, particularly when they were related to the idea of "looking good" or "being healthy." One patient responded to my question "what does being healthy mean to you?" by smiling and saying "you look pretty healthy to me, radiant and so on," and another responded to our discussion about the importance of "beauty" by saying "you're a pretty girl, you know that looks matter." When introducing me to his son via Skype, one participant gestured towards me and said "this is the cutest doctor you'll ever see" before answering my question about how he gained his diagnosis. Half way through our interview another participant said "by the way you ask very good questions, and this is a little bit off topic but you have a beautiful smile as well." Because most of these interviews took place over Skype or FaceTime, these comments did not make me feel uncomfortable in the same way that they might have done if the interviews had taken place face-to-face. However, I do not doubt that these reactions shaped the way that these participants responded to my interview questions, or that they potentially shaped my subsequent interactions with these participants during later interviews.

[20] During her interview, one AKU patient discussed how she was told by her doctor that, if she were to have children, her breast milk might be dark. This discouraged the patient from having children, as she felt that she would be unable to provide her children with "clean" milk.
[21] For example, with "normal" (i.e. white) breast milk.

Experiencing Stigma: Narratives of Precarity, Vulnerability and Loss

> With AKU you're hurting everywhere, your back is hurting and your neck is hurting … you're just walking around looking like a normal person really and you're in pain. Nobody really knows you're in pain and they treat you like you're a normal person because why wouldn't they? And it's like you don't want to explain it to them and say look don't treat me like a normal person because you want to be treated like a normal person. I don't know - it's hard to explain. It's kind of lonely … I just want to be seen as normal but I also want disability [benefits] at the same time. I worry that I'm not going to get disability [benefits] because they don't know nothing about the disease. And *I am* disabled, I'm not pretending.
>
> (Janet, AKU, original emphasis)
>
> I'm always wondering why my own race can't see me [with vitiligo]. And then the white girls I dated they saw me, and I always was shaping my racial identity because of that. Like what did I do to them [white women] that they can be all over me? … If they see me and they're with their friends they'll come running across the street and jump in my arms and give me a hug and then the black girls that say they're friends with me on social media they don't do the same thing, you know? They don't even acknowledge me when we're out. So I'm always battling like why can't they [black women] *see* me?
>
> (Austin, vitiligo, original emphasis)

These two statements, the first from an interview with Janet, a Native-American AKU patient in her mid-40s, and the second from Austin, an African-American vitiligo patient in his early-40s, outline one of the key challenges that chronic disease patients often face when out in public –being *looked at* and not being *seen*. Janet's recognition of the ways in which people overlook her pain because it is not immediately visible to them causes her to question whether she would prefer for them to see her pain and treat her accordingly. Seeing her pain, she infers, would allow them to recognize her struggles in dealing with it, which, in turn, would legitimize and validate her experiences of it. If people were able to *see* her pain they would not assume that she was "pretending" to be disabled in order to receive disability benefits. Instead, they would view her in a way that more closely aligns with the way that she views herself - as a person who is not "normal" because of her everyday struggles in managing a disease

that is both chronic and debilitating.

Austin differs slightly in his awareness of how he is marginalised by certain groups of people but not by others. Black women, he argues, do not "see" him because they cannot see beyond his appearance, which makes clear his extensive vitiligo. He further notes that when black women look at him they immediately dismiss him as someone to be avoided, but then go on to form superficial friendships with him on social media. Austin believes this to signify their refusal to get to know him on a personal level, which, for him, is tantamount to rejection. As a result, Austin is left feeling alienated and marginalised by a group to he feels affiliated to as a black man.[22] For both participants, the experience of not being seen in relation to the ways in which they see themselves causes feelings of alienation and invisibility. Their awareness how they are stigmatized because of their visible and invisible differences (Austin's extensive vitiligo and Janet's debilitating chronic pain respectively) causes them to question how they are "seen" and whether or not they want to be "seen." Austin is left questioning why his "own race" can't see him because of his vitiligo, and Janet deliberates between the benefits of being seen in relation to her disease (which would grant her recognition of her daily struggles in coping with it) and not being seen in relation to it (which would allow her to be treated as a "normal person").

As outlined in the introduction to this thesis, stigma occurs when the "gaze" comes into contact with the "other" and recognises a dissimilarity or abnormality. As a result, the stigmatized subject always deviates from prescribed social norms and/ or from social expectations. These norms and expectations are often related to physical appearance and behavior. When we come into contact with another person we automatically make assumptions about them based on how they look or what they are doing at that moment (Garland-Thomson 2006). Shortly after we make these assumptions we often recognize that we have made them too quickly and we correct them, particularly if we then go on to engage in conversation with that person and get to know them personally (Garland-Thomson 2006; Garland-Thomson 2009). However, it is also the case that, when the object of the gaze does not conform to the presuppositions that the gaze initially makes about them, that person is often rendered "strange," "unknowable," and even dislikable.[23] When a person is chronically ill, and their illness visibly marks itself on their body, he or she is often stigmatized when in public because they "look different" from what is typically expected (i.e. that they "look healthy") (Gilman 1999; Berry 2016). Typically, this expectation centres on what is considered "normal" in any given context (Goffman 1990).

[22] This rejection prompted Austin to reconsider his racial identity and his dating preferences. During the interview Austin later told me that he tends to romantically favor white women because they are less likely to embarrass him because of his appearance when in public. White women, he argued, are more likely to accept his vitiligo and see past it. This, in turn, meant that they were more likely get to know him on a personal level and see him separately from his vitiligo.
[23] I call these "presuppositions" because the "gaze" has yet to "see" the subject (they are *looking* at them and not *seeing* them).

In neoliberal economies where "looking healthy" is often mistakenly understood to be indicative of an individual's "good character" and capability (Reid & Clark 2002), "looking unwell" or "abnormal" is often mistaken as a sign of that person's inability to care for themselves and/ or their inability to work. As argued by Hannele Harjunen in her contemporary study of neoliberal bodies and "fatness" in "the West," "the fat body has become emblematic of failure in the embodied performance of control. This is a grave matter in a culture where the ability to control one's body, most acutely manifested in the ability to control one's body size, has become an all-important standard, not only for health but also attractiveness, social acceptability, morality, and productiveness" (Harjunen 2017, p.9).

The ideological disjuncture between those who stigmatise and those who are stigmatised can (and often does) result in conflict, wherein both seek to (re)define what is considered "normal" and/ or "acceptable" in different social locations.[24] The HIV/ AIDS crises of the 1980s saw young gay men and intravenous drug users being targeted by numerous public campaigns that sought to demonise those who were infected and highlight the supposed "risk" that they posed to the broader population (Berger 2004; Persson & Richards 2008). These campaigns purposefully emphasised the ways in which HIV/AIDS can be transmitted through gay sex and intravenous drug use, and by doing so further demonised behaviour that, for many, was already considered "immoral" and/ or "deviant" (Kantor 1998). As a result, these two groups were heavily stigmatised and often socially and politically marginalised. In response to this backlash, several HIV/AIDS activist groups were formed to support those who had been marginalised because they were HIV/ AIDS positive and campaign for clinical funding (Gould 2009; Hutchison & Hutchison 2015). Thus, by "fighting back" they sought to challenge the routine stigmatisation of those who were HIV positive, and offer new definitions of what being positive meant for those who were living with the condition (Gould 2009).

In their study of stigma and (in)visible chronic conditions, Gloria Joachim and Sonia Acorn note that visibility "plays an important role in producing negative social reactions" (Joachim & Acorn 2000, p.244). Thus, according to both authors, negative social reactions are largely the result of visible differences that mark certain individuals as "other" or "dissimilar" from the majority. If a chronic condition is highly visible it produces negative social reactions, and if it is largely invisible it does not. In other words, the degree to which an "abnormality" or "difference" is visible determines whether or not the individual will experience stigmatisation. Goffman supports this idea by noting that visibility is a "crucial factor" in determining the likelihood of

[24] For those who are stigmatised, it can also result in symbolic violence whereby the stigmatised individual internalises and (often unknowingly) reproduces the stigmas that they are given.

stigmatisation (Goffman 1990, p.65). For AKU patients, the relative invisibility of their condition stems from two key factors: firstly, because their condition is largely unknown, it is unlikely that their symptoms will be read in relation to AKU. Secondly, because the visible symptoms that coincide with this disease as it progresses are similar to those that occur as ordinary people age (i.e. decreased mobility), it is likely that patients will be mistaken for simply "getting older" as and when they experience them. As noted by one patient:

> You know when you get in your 60s and you're kind of moving along in age you naturally slow down. A lot of people my age aren't doing as much as they used to anyway, you know? And so it's not like it's all that unusual … the limitations I have are not that much different from those that a lot of people my age have.
>
> (David, AKU)

For David, the physical limitations that his symptoms cause are similar to those that are experienced by others his age who do not have a medical condition. As a result, he is able to avoid being labelled "different" from his peer group, which affords him a type of invisibility that allows him to remain "unseen" in relation to his condition. This is a common experience amongst AKU patients who are in their late 50s/ early 60s. The steady decline in their physical abilities is viewed as "normal" because of their age and, as a result, they are able to chose if and when to disclose information about their disease. As I will later discuss in my chapter on passing, this, in turn, affords them a significant amount of control over the ways in which others view them, and often allows them to pass as "normal" or "unaffected" if they choose to.

People with vitiligo who have extensively depigmented are typically not afforded this opportunity. Subjects who have large affected areas of skin often find it difficult to effectively conceal these areas from view, and are, therefore, typically unable to pass as "normal" or "unaffected" by their condition. Because vitiligo is often highly visible,[25] people with this disease are typically subjected to stigmatisation from those who assume that it is "contagious." Those who make this assumption often conclude that the individual poses a risk to others around them, and that they should, therefore, be socially avoided. During their interviews numerous participants discussed incidents wherein people assumed that their disease was contagious and, as a result, refused to shake their hand or eat any of the food that they offered them. This, they argued, was because both would involve some form of physical contact that others believed would

[25] Note that the hypervisibility of vitiligo is largely dependent on the affected area. Vitiligo in areas that are typically concealed from members of the public (i.e. the stomach) is less visible than areas that are typically shown (i.e. the face).

put them at risk of infection.[26] One participant claimed that, when she was a teenager working in an ice cream shop, a customer complained to her manager about her serving and handling their food:

> I worked at an ice cream shop through middle school and high school and we had a drive through window. And so when I would hand people their cones or ice cream they would see my hands, and I never thought anything of it because it's not catchy [contagious] you know? So a couple of weeks later my boss who happened to be a friend of mine she came in and she's like "hey I just got this letter in the mail and someone was complaining that someone with some skin disease was working with food and handing people their ice cream" and I was like so, why are you telling me this? And she's like "they're talking about you Jennifer" and I'm like no way!
>
> (Jennifer, vitiligo)

Knowing that her condition was not contagious, Jennifer did not hesitate to seek employment in an ice cream shop where she knew that she would regularly be handling food and interacting with customers. Responding with shock to the customer's complaint, Jennifer was disturbed by the fact that someone could mistake her condition for one that is contagious and then infer that she was not suited to work with food. As a result, she was left feeling confused and rejected by a customer who made her feel that it was inappropriate for her to work there because of her vitiligo.

I will begin this chapter by discussing the relationship between experiencing stigma and disease visibility. By considering the role that beauty plays in reproducing norms that shape and outline what it means to look "different," I will discuss how participants from both disease groups seek to avoid stigmatisation as a result of looking "different" by engaging in well-known beauty practices. Following on from Jennifer's story, I will further consider how public misconceptions about symptoms from both disease groups can result in a fear of contagion, which inevitably leads to stigma (Wald 2008). I will then turn my attention to the importance of controlling the "gaze" for participants from both disease groups who seek to minimise and/ or avoid being stigmatised. By using the work of Goffman and Du Bois to outline the alienation and "unknowingness" that comes from being stigmatised and, in many cases, invisibilised because of stigma, I will show how the patient's ability to exercise control over the way that they are seen often results in feelings of body confidence and a desire to "be visible."

[26] Note that vitiligo cannot be transmitted in this way.

Experiencing Stigma

In the US, beauty is often conceptualized in relation to health (Wolf 2002; Hamermesh 2011; White et al. 2013). Those who are considered "beautiful" are also typically considered "healthy," and this often leads to social and material benefits that disproportionately advantage those people (O'Connor & Gladstone 2018; Hamermesh 2011). If stigmatization is caused by a deviation from prescribed social norms, and these social norms include the expectation that individuals will "look healthy" when in public spaces, beauty can be understood as a way to avoid stigmatization. It is important to note that "beauty" is both a subjective and an objective construct (Wolf 2002; Berry 2016). What and who is considered "beautiful" alters in accordance with context, and is largely dependent on the individual preferences of the observer. As the popular saying goes: "beauty is in the eye of the beholder." However, there is also a widespread understanding of what constitutes "beauty" that is largely supported by ideals that are propagated by the beauty industry. Media advertisements that instruct viewers about the latest make up trends and fashion items shape national and international understandings of, and conversations about, what constitutes beauty and how beauty can be achieved (Stuart & Donaghue 2012; Peiss 2011). As noted by Daniel Hamermesh in his study of the economic value of beauty, "[y]ou and I may differ in our views about what beauty is. But if our views about human beauty are somewhat similar, and we are typical individuals, then our opinions are valuable representatives of how the general population views beauty" (Hamermesh 2011, p.22). Whilst Hamermesh overgeneralizes by making claims about who the "typical individual" is and how they think, he succinctly outlines how notions of objective and subjective beauty measures overlap when considering what constitutes "beautiful bodies" and "beauty norms." Whilst we might individually disagree on the subject of who is *most* beautiful when asked to choose from a list of people who have been nominated for *People* magazine's "World's Most Beautiful" award, it is likely that we will consider all of the nominees to be "beautiful" in some respect because they adhere to socially understood ideas of what beauty "is" and what it "looks like."

Contrary to Hamermesh's claim that "[b]arring disfiguring accidents, we are basically stuck with what nature and perhaps early nurture have given us," beauty is something one can *achieve*; or, as Toni Morrison argues, beauty is something one can "do" (Morrison 1999, p.205). Vitiligo participants often claimed that when they first started developing "white spots" they covered them with make up in order to conceal them from public view.[27] This, they argued, made them look and feel "beautiful" because their skin did not show any marks or signs of "disfigurement." However, when their vitiligo began to spread to parts of their body that were difficult to conceal, participants were typically faced with two choices; to either stop covering their depigmented skin completely or to seek alternative and potentially harmful treatments that may generate large-scale re-pigmentation. The most widely used (and

[27] "White spot" is a term that vitiligo participants often used during their interviews to describe small depigmented areas of their skin.

arguably the most effective) treatment is light therapy, which involves the person with vitiligo standing directly under UV light for prolonged periods of time in order to encourage re-pigmentation (Thomas 2007; Woloshyn 2013). This treatment can dramatically increase the patient's likelihood of developing cancer, and its success rate depends on both the patient's susceptibility to the treatment and where the affected area of skin is. The patient may fail to respond to the treatment or the area of skin that they wish to repigment may be too difficult to treat. The latter typically occurs when the affected area of skin covers the patient's knuckles, knees, or ankles.[28]

As well as covering their "white spots" in order to achieve "beauty," vitiligo participants also often cover them in order to gain employment, particularly in sectors that require front-facing customer interaction or the handling of food. When asked if they have ever been concerned about getting jobs in these sectors because of their vitiligo, most participants claimed that they had and that they were also worried about how their disease would affect their job prospects in a range of industries. One participant who had been diagnosed with vitiligo at six months old said that his awareness of "corporate America's beauty standards" made him aspire to work as a history teacher in a museum rather than in a school. Although both would involve interacting with other people, the former would involve less interaction, which he believed would increase his chances of getting a job. Another patient who developed vitiligo in her late 40s claimed that she had previously been interested in working at Starbucks but, after she began developing "white spots," she no longer thought it likely that she would get a job at this company because others might be wary of her handling their beverages:

> I wouldn't mind working at Starbucks .. but I thought that's probably gonna be hard because I probably would have to keep gloves on you know regardless you know of whether or not they [other staff] wear gloves. But I thought to myself I probably would have to wear gloves because they probably wouldn't want me touching their coffee or making their coffee … so the food industry I think would be hard for a person with vitiligo to get a job.
>
> (Linda, vitiligo)

For Linda, the likelihood of her being required to wear gloves whilst working in Starbucks because her managers, other members of staff, and customers would likely presume that her disease is contagious is a key reason why she decided not to enter into this profession. The indignity of wearing gloves when none of the other employees would have to, and the futility of wearing them when she knows that her disease is not contagious, would likely cause her emotional distress and could, potentially, further ostracize her from other members of staff who might already be wary of her because of her condition. Another participant recounted

[28] During their interviews numerous vitiligo participants related how their knuckles, knees and ankles were particularly difficult areas of their body to conceal.

how, when he was 20 years old, he sought employment in several fast food restaurants but was rejected because employers presumed that his disease was contagious and, as a result, did not want to hire him. Before he started his job search this participant had been selling drugs for many years in his local neighbourhood. Gaining a job in the fast food industry and outside of this environment would have offered him an escape from his immediate environment, and would have given him the opportunity to "go straight" for the first time in his life.[29] For this participant, his rejection from these positions meant that he was left with no other choice but to return "to the streets" where he knew he would be accepted with his condition:

> When it was first turning [skin turning white] anytime I was trying to find a job people would not hire me because they thought it was some type of contagious disease and they were afraid that their business would suffer and people wouldn't want to do business with them … It's really sad when a person can't get a job at like McDonalds or get a job at Taco Bell, it's like man that's almost demoralizing if you can't get a job doing that type of work and no one will hire you. … it's debilitating in a way, you know? It's mentally debilitating I should say. So you know you don't want to even be around that whole environment … you're just like man I need to get on up out of here and get back to where they accept me and where they accepted me was on the streets.
>
> (Anthony, vitiligo)

Anthony's repeated exposure to discrimination in the job market meant that he eventually abandoned his job seeking efforts and resumed his criminal lifestyle. This subsequently led to numerous stints in prison, during which time he experienced an onset of two other chronic conditions, lupus and fibromyalgia, which further diminished his overall quality of life.

Because having vitiligo could potentially discourage people with it from entering into certain professions or, indeed, from seeking even low-skilled and low-wage jobs, it is reasonable to argue that this disease could prevent that person from acquiring financial capital. That is not to say that there are not people with vitiligo who *do* seek employment. Almost all of the participants that I spoke to were, at the time of the interview, either employed or in full-time education. It is, however, to suggest that people who have vitiligo often think about the ways in which that might affect their job prospects, which might make them hesitant when applying for certain positions. As noted by one participant when discussing his hesitancy before and during job interviews, "when a person with vitiligo walks into a job interview the first thing on their mind is you know will my skin condition hold me back? Will the manager ask me

[29] Note that I will return to this participant in chapter 4: "Being a Good Patient: Inequality, Visibility and Personal Responsibility."

about my skin? And if he does ask me after I tell him what it is will he be ok about me working there?" If a person's body, and how employers perceive that person *in relation to* their body, is important in determining his or her success in acquiring a job it is easy to see why people with visible conditions might think it important to invest time, energy and money into "correcting" their appearance by covering what others might perceive to be signs of "disfigurement" (O'Connor & Gladstone 2018). In this way, the vitiligo participant's choice to conceal their vitiligo could be viewed as not only a means through which to achieve "beauty," but also as a way of ensuring financial security.

During their interviews participants from both disease groups routinely discussed how they felt they had been socially ostracized because of their disease symptoms at various points over the course of their disease. Many noted that this was primarily because others misjudged their symptoms and assumed them to be contagious. One AKU patient recounted how, upon discovering her diagnosis, her neighbor discontinued her yearly invitation to a pool party that she hosted in their local community. According to this patient, after this woman researched the disease online and found out that her sweat was "black," she decided that it would be unhygienic for her to swim with the other guests:

> We went to a pool party on July 4th like every year and I mean the moment I got diagnosed, yeah the moment she heard I sweat black, she decided no more in the pool. Yeah she told our neighbor "oh I won't have her in my pool" because it's unhygienic. Yeah and then they [other neighbours] were doctors and they felt bad for me so they had me over, you know because I was like oh ok [upset]. But at that point I felt bad and thought well that is kind of gross, sweating black. I kind of started thinking like they did … but then I'm like why would they say that, you know? … I can't help it, you know what I mean? It's like I can't help it, it's nothing you know that I've done. It was pretty crazy, I mean yeah that was a difficult thing because I'd just been diagnosed and then that happened and I was feeling pretty low already.
>
> (Claire, AKU)

Upon hearing that her neighbor had assumed that her dark sweat was indicative of her "uncleanliness," Claire began to question a symptom that, up until that point, she had been largely unconcerned about. Because she had recently been diagnosed with AKU, she was still coming to terms with what the disease meant for her and how her disease symptoms might disrupt her life. Believing her dark sweat to be "kind of gross," Claire started to see herself in relation to how her neighbor saw her, despite knowing that her neighbor had a limited understanding of what AKU actually is and what it meant for her in relation to her symptoms. Recognising that her dark sweat was neither harmful

to other people nor a sign of uncleanliness, her other neighbors, both of whom were doctors, invited her to their house to socialize with them. Gradually, Claire developed the resilience that she needed in order to recognise the unfairness of her neighbor's initial judgements. She gradually came to realize that her disease symptoms are not her fault ("it's like I can't help it, it's nothing you know that I've done"), which eventually boosted her self-esteem.

Whilst people with vitiligo typically note that others see their disease and immediately assume that it is contagious, AKU patients often argue that, when it comes to debilitating symptoms such as chronic pain, the relative invisibility of their suffering goes unnoticed by other people. This, in turn, means that people often fail to believe them when they are in pain, which can (and often does) cause feelings of anger and frustration from patients who feel unable to effectively communicate their experience of it.[30]For patients who seek disability benefits because of their chronic pain, this becomes even more challenging. Those who do not believe that they are in pain are typically reluctant to accept the fact that they have a genuine need for their disability claims, which often leads to accusations of "misusing" the public welfare system. This, in turn, can result in stigmatization, wherein the patient is rendered "lazy" and/ or "incompetent" in their approach to work rather than physically unable to work. An example of this can be seen in Janet's opening statement, where she relates her concerns about not receiving disability benefits because state officials who approve these claims "don't know nothing about the disease" and, therefore, are unlikely to grant her request.

In response to others' failure to recognize their chronic pain and the ways in which it negatively affects their lives on an everyday basis, AKU patients often create and/ or use tools that signal to onlookers that they have a medical condition. These tools often prevent the patient from being labeled a "complainer" who has no "real reason" to complain. During her interview, one AKU patient discussed how she purposefully sought out a bumper sticker to attach to her car so that, when she parked in public disabled spaces, she could avoid confrontation from other motorists who would otherwise assume that she should not be using them. Drawing on past experiences of being told that she should not park in these spaces because she was "not disabled," this patient pre-empted this response from others and deliberately sought to make the fact that she has a debilitating chronic condition known:

> You may not have noticed but on the back of my car I've got a sticker on it, it says "not every disability is visible." I found it through the internet, I got it on Amazon. It was very important to me, and I got a few of them and I gave them to friends that are you know disabled … because that's the whole point, you can't judge a book by its cover … I remember one day parking in a disabled spot and

[30] I will return to this subject in chapter 3: "(In)Visibilising Pain in Response to Chronic Illness."

> this guy coming over to me and shouting at me, [saying] "what are you doing parking there? You're not disabled!" and I was like excuse me? You know nothing about me! And it was really horrendous and I thought how dare you? But it's just this old you know stereotype that if you're not in a wheelchair you're not disabled.
>
> (Amy, AKU)

Unlike people who have chronic conditions that require them to use a wheelchair, Amy was subject to routine questioning about whether or not she was "deserving" of a disabled parking space because her disease is invisible and she does not require constant mobility support. Amy responded to these comments by challenging this man's preconceived notions about what disability is and what being disabled "looks like," and in doing so showed her resistance to this form of intimidation. In this way, the bumper sticker that Amy displayed on her car acted as both an educational tool and as a way for her to exercise control over how she is seen in relation to her condition.

Controlling the Gaze

In his study of self-presentation and public interaction, Erving Goffman uses the term "front" to describe an actor's tools, props and "fixed" bodily markers that enable and facilitate their social performance (Goffman 1959, p.22).[31] He further claims that "[w]hen we think of those who present a false front or 'only' a front, of those who dissemble, deceive, and defraud, we think of a discrepancy between fostered appearances and reality" (Goffman 1959, p.59). By arguing that we are able to distinguish between an actor's performed and authentic "realities," Goffman infers that the actor's identity is always either performed *or* authentic. Presenting a "false front" means that one is, at that moment, performing an identity that is disingenuous and, therefore, disconnected from one's "authentic" self. It is important to note that the distinction that Goffman makes between "fostered reality" and "reality" is neither new nor original. As stated in my introduction to this thesis, W.E.B Du Bois's theory of "double consciousness," first published in his perennial text *The Souls of Black Folks* in 1903, outlines the conflicting nature of having two identities that are seemingly discordant. For Du Bois, being both a "Negro" and an "American" presents a challenge for African-Americans who cannot reconcile both identities in a systematically racist society that prevents them from existing conjunctively.

Du Bois further claims that this dual identity necessitates a recognition of the ways in which African-Americans are seen, and highlights the likely differences between how they are seen

[31] I use quotation marks for the word "fixed" here because some of the bodily markers that Goffman describes are subject to change i.e. a limp, age, clothing etc.

and how they see themselves. He states: "the Negro is a sort of seventh son, born with a veil, and gifted with second-sight in this American world, - a world which yields him no true self-consciousness, but only lets him see himself through the revelation of the other world" (Du Bois 2018, p.3). Unlike Goffman's claim that the solitary presentation of "front" arouses suspicion in those who doubt whether the subject is conveying "fostered reality" or "reality," Du Bois's theory suggests that one's "reality" cannot be seen beyond one's "fostered reality." There exists a refusal to *see* the black subject as both black and a US citizen because these two identities do not coincide within the US. This refusal to see, Du Bois infers, results in a misrecognition that causes whites to see blacks in relation to a caricatured articulation of what it means to be black that does not allow for their individual subjectivity. In this way, blacks are viewed as collective representations of a singular identity that does not allow for personal inclinations, viewpoints or agendas (Carbado & Gulati 2013). As a result, whites are fooled into believing that the performance of "self" that the black subject enacts is an accurate and truthful depiction of their character (Hughes 1962). By failing to recognize their performance as *performance*, they see only what they wish to see – the black subject's conformity to stereotypical representations that mark him or her as socially and culturally inferior (Hughes 1990; Ellison 1995).

Black people with vitiligo often operate within the limits of double consciousness whilst having the additional burden of being highly visible because of their condition. If double consciousness signifies a type of invisibility for black subjects who are hidden behind a collective identity that they individually "represent," then black subjects with vitiligo are simultaneously rendered invisible and hyper-visible because of the visible differences in their appearance.[32] Austin, quoted at the beginning of this chapter, presents an interesting case study, as his invisibility stems from the failure of *black* people to see him separately from his disease rather than white people. This, I argue, represents an *inversion* of double consciousness, by suggesting that black people with vitiligo are "unseen" by other *blacks* because of visible differences that are, to many, unknown and/ or misunderstood. Unlike black women, *white* women are able to look past Austin's appearance and "see him" in relation to who he is, which renders him "visible" when in their company.

As someone who began to show signs of vitiligo at the age of six months, Austin had become used to the negative stares and comments that his appearance often attracted at the time of the interview. Growing up in a predominantly black community in rural Georgia, Austin was often subjected to physical and verbal abuse because of his vitiligo. During the interview he often referred to a period in his life where he routinely "snapped" and reacted violently to the stares and taunts that he would regularly receive. He claimed that, during this period, he would "fight all the time" in order to gain respect and recognition from his peers and family members who would commonly carry out this abuse:

[32] As previously stated, the visibility of the black person's vitiligo depends on where the depigmentation occurs, and the extent of that depigmentation.

> At one point I just didn't take a lot of stuff off people. If people said "what's wrong with your skin" I was ready to go and punch somebody, you know what I'm saying? And then I kept fighting and I was like damn every day I'm fighting somebody and I knew I wasn't that guy and you know, I had to change my life and that's when I did. I started playing sports … and that's how I just turned myself into who I am now.
>
> (Austin, vitiligo)

In order to resist the deeply damaging affects of his internalization of their recognition of difference, Austin felt that he had no other choice but to "fight" his attackers in order to challenge their preconceptions of him. Doing so meant that he gradually became a person who he no longer recognized and, as a result, he decided to play sports in order to positively channel his anger. Austin's violent response to frequent stares and comments about his vitiligo is not an uncommon reaction. During their interviews, several participants with vitiligo related how they had reacted violently on numerous occasions when provoked by members of the public who either outwardly conveyed disgust when looking at them or insensitively inquired about the cause of their disease. One participant claimed: "as far as like growing up with [vitiligo] … I was mean, it made me mean … I stayed on defense at all times. I was already on defense thinking you know what is this person getting ready to say?" Another participant, Amanda, discussed her violent reaction to a customer in a shop that she worked in who did not want to take money out of her hand because he feared that he would "catch" her disease:

> When I first started working there [shop] it used to upset me and offend me [people not wanting to take money from her hand], and one time I threw the money at a guy. I was so upset because of the way he just you know hesitated to take the money from me … I was just mad and just threw it.
>
> (Amanda, vitiligo)

By hesitating to take the money from her hand, the customer made Amanda feel "dirty," which then led to sentiments of shame and embarrassment that prompted her to respond violently. These sentiments contributed to an overall feeling of stigmatization, which reminded Amanda of the fact that she was "different" from prescribed social norms. To her, his reaction also signified an absence of human recognition by showing his failure to understand the ways in which his hesitation could

negatively affect her self-esteem.[33]Responding violently allowed Amanda to resist the damaging affects of the gaze by reclaiming agency over how she was viewed by the customer. By throwing the money at him she was able to demonstrate her autonomy as someone who rejected his conceptualization of her as someone who should be avoided and, potentially, pitied. In this way, Amanda was able to subvert her default position as a "victim" of the normalizing gaze that rendered her "different" or "unusual," and present herself as a person who could resist the gaze by "fighting back."

AKU patients with noticeable gaits are often rendered "suspect" by those who read their symptoms as "evidence" of their drug and/ or alcohol addiction. However, unlike people with vitiligo, AKU patients who have this experience do not typically react violently when confronted or shunned by members of the public. Instead, the patients that I interviewed largely reacted sympathetically to those who misread their symptoms in this way. As noted by one patient, Christopher, when recounting his experiences of interacting with others and being mistaken for a drug addict and/ or alcoholic:

> I've found that [pause] you know if I'm walking strangely and I'm not using a walking stick people, they don't know what they're dealing with. They don't understand. They might assume that you're drunk or they might assume that you're high and so they're not instantly helpful or friendly or you know anything like that. Whereas I've found that, when I'm using a walking stick, people open doors for me and people let me sit down you know … where it might be standing room only people are far more accommodating and friendly, and this you know it's not like you know this bothers me. I understand it having dealt with this for so long in so many cases and having been around friends you know in similar situations …. I totally understand it and it doesn't bother me in the slightest you know if someone looks at me if I'm not using a cane and … you know assumes the worst, assumes I'm drunk. I totally get it, I totally understand it and I'd probably do the same thing. And I understand why you know when I use a cane … they're more accommodating and they're more generous and they're more friendly or whatever, I totally understand that as well.
>
> [Christopher, AKU]

By claiming that he "understands" why people assume that he is "drunk" or "high" because of his affected gait, Christopher excuses the onlooker's mischaracterization of

[33] As noted by Erving Goffman in his work on stigma, "we believe a person with a stigma is not quite human" and, because of this, "we exercise varieties of discrimination, through which we effectively, if often unthinkingly, reduce his life chances" (Goffman 1990, p. 15).

his symptoms by arguing that their assumptions are "understandable." He supports this sentiment by claiming that he would "probably do the same thing" if he was in their position, and in doing so relates his understanding of how his body could be interpreted by audiences who are unfamiliar with AKU and/ or who are unable to recognize its symptoms. Moreover, by implying that their response is justifiable, Christopher infers that avoiding people who are addicted to drugs and/ or alcohol is a natural response that all people should have when they encounter people whose bodies and/ or behavior seemingly suggests this. During their interviews numerous other AKU patients with noticeable bodily differences often conveyed similar sentiments, with many arguing that those who questioned their visible differences often conveyed *curiosity* rather than contempt. One patient, James, described an encounter that he had with two women in a grocery store who commented on the noticeable pigmented "spots" in his eyes. Turning to him, one said "I love your eye colour!" in order to start a conversation with him about it, and find out why his eyes were noticeably pigmented. Rather than responding angrily, James explained what it was, laughed, and later said that he found the whole conversation "kind of humorous." By responding in a way that clearly showed that he was not offended by this woman's remarks, James implied that he did not feel threatened or stigmatized in any way because of them.

If both disease groups experience marginalisation and mischaracterization because of the visible ways in which their bodies differ, why do their responses to these experiences differ? Why is it that people with vitiligo are more likely to respond with hostility and/ or violence to onlookers who point out their visible differences than people with AKU, who often respond sympathetically? I would argue that the relative visibility of vitiligo means that people who have it are more likely to experience stares and confrontation on a regular basis, which, in turn, means that they are more likely to *anticipate* these stares and reactions when out in public. This anticipation typically leads to increased feelings of vulnerability to attack, which means that they are more likely to react with hostility when confronted by those who react negatively towards them. In addition, because they anticipate these reactions, people with vitiligo are more likely to recognize when others are staring at them. Whilst conducting my fieldwork in Washington DC I visited a museum with one vitiligo participant, Linda, and her family. Whilst we were waiting in a line for entry to the museum, we began discussing vitiligo and the ways in which it often attracted public attention. Linda noted that, at that moment, other people in the line were staring at her. As she said this her eyes were fixed on mine, and they did not move as she called attention to specific people who were staring on either side of us. My field notes are useful here in detailing my immediate responses to this conversation:

> We were standing in line for the first exhibit when the topic of vitiligo was initially raised. Linda raised it, and her face became more and more

> animated as the conversation continued. She told me to look around at the other people in the line because they were staring at her. She said all of this whilst she was looking at me, and she raised her sleeves to bait them and attract more attention and stares from people so that I could see their reactions. She kept looking at me and said "just look, do you see them looking?" and then further baited viewers by rolling up her sleeves even more. I saw an older white woman look at her curiously. Linda kept her head down to avoid eye contact with them and made it evident that she could feel them staring at her. She then went on to talk about how she is constantly aware of them staring at her without actually looking at them, and she was right because people were staring at her. I could see it after she pointed it out. How did she know that they were looking at her without also looking at them?
>
> (field notes, March 2017)

Before Linda noted that people were staring at her I was not aware that they were, perhaps because I was speaking directly to her and not paying attention to the other people around us. At the time Linda's vitiligo was highly visible and had spread to areas of her body that were regularly exposed to the public (i.e. her face, neck and hands). Yet despite its visibility, I did not find her vitiligo shocking or "abnormal," perhaps because I anticipated seeing her with it. As a result, I was surprised to see the amount of people who were staring at her. In response to my surprise, Linda purposefully positioned herself in a way that would allow me to see the full extent of their reactions.

Conceptualising Disease Progression in Relation to Stigma

As previously noted, it is usual for AKU patients to undergo numerous joint replacement surgeries over the course of their life, and for this to become more frequent as the patient ages and their disease advances. It is also usual for patients to notice visible signs of their disease as they age (i.e. an affected gait and ochronosis), and for them to gradually become more self-conscious about their appearance as this happens. This, in turn, means that patients are more likely to experience depression and related mental illnesses in relation to their disease as they age.[34] Because patients are likely to start experiencing debilitating symptoms in their late 50s/ early 60s they are often able to relate their symptoms to ordinary signs of ageing, which typically decreases the overall level of stigma attached to them.[35] As a result, when they begin

[34] Patients typically reported feeling more "conscious" of their disease and the negative effects that it was having on their mental health as they got older.
[35] I do not wish to suggest here that these symptoms are always stigmatised, but rather that AKU patients reported feeling able to "hide" symptoms that they might have otherwise been stigmatised for when they were younger by attributing those symptoms to ordinary signs of ageing.

to experience severe symptoms, it can be difficult for patients to distinguish between signs of disease progression and ordinary signs of ageing.[36] Consequently, patients are more likely to overlook disease symptoms that seem 'normal' given their age, and are less likely to raise concerns that they have about these symptoms with their doctors. During his interview one patient attributed that fact that he can now no longer do some of the physical activities that he once enjoyed to both ageing and his AKU. He further described how it is often difficult to distinguish between the two in terms of his physical symptoms:

> I used to do a lot of back packing and things that were kind of high intensity, these are things that I can't do anymore. Part of that though is just getting older, you know? At 65 you're not going to be able to do as much or do it as well as you did at 35 and 45. So sometimes it's a little hard to distinguish between the two, with the limitations of alkaptonuria and the limitations of just getting older.
>
> (David, AKU)

David's inability to distinguish between signs of ageing and signs of AKU progression means that, together, both inform his embodied understanding of his physical limitations. Conceptualising his disease in this way makes it easier for David to cope with the physically and socially debilitating affects of AKU as it allows him to relate to his peers through a shared understanding of what it means to experience these symptoms. This, in turn, makes David feel less isolated when coping with the disease. People with vitiligo are only able to relate to their peers in this way if and when they completely depigment. Because the shape and size of the individual person's depigmented skin and the rate at which the disease spreads varies person-to-person, it is highly unlikely that they will encounter another person who has the exact same "spots" in the same areas. This, in turn, means that there will likely be a disconnect between that person and another person with vitiligo in terms of their lived experiences. Some might argue that they are "worse affected" by the disease because, on them, it has spread to highly visible areas, such as their face and hands.

Complete depigmentation presents unique health challenges for people with vitiligo, the most prominent of which is the likelihood that, at some point over the course of their disease, they will experience skin damage after long periods of sun exposure (Papadopoulos et al. 1999). Because they do not have melanin in their depigmented areas of skin, they are not protected from the skin damage that is often caused by UV exposure, which means that they often have to stay out of the sun completely or cover

[36] For people who are currently living with AKU but have not been diagnosed, this could provide an explanation for the relatively low rates of AKU diagnosis in the US.

their skin with clothing and high SPF sun lotion.[37] Participants who had completely depigmented often claimed that not being able to be in the sun for long periods of time was one of the most difficult and debilitating affects of having the condition. This was largely due to the fact that they could no longer fully participate in activities that took place outdoors during summer months, many of which involved spending time with their family members and close friends.

People with vitiligo who have completely depigmented are often understood to be relatively advantaged when compared with people who have partially depigmented because they do not typically attract the same amount of stares and attention. As I will argue elsewhere in this thesis, this often affords the depigmented person a type of invisibility that allows them to pass as "light skinned" or "naturally pale" depending on their racial identity. As a result, within the vitiligo community it is often assumed that people who have depigmented have a better overall disease experience, and are not stigmatized because of their appearance. However, during their interviews depigmented participants often claimed that, whilst they were often able to pass as "normal" in public spaces, they were routinely marginalised within the vitiligo community because they were not thought to share the same experiences as the majority of people who were still "transitioning."[38] For many, the contrast between the latter's original and depigmented skin meant that their disease was significantly more visible, which, in turn, meant that they had a worse overall disease experience. During her interview, one participant who had depigmented inferred that this compromised her position as a vitiligo advocate because it made her experiences different from the experiences of the majority of the people that she was representing:

> Before, when I was going through the transition, I was a little more relatable, you know? … but now it's different. [People with vitiligo are] like "well look at you, you're fine [because] no one can tell [you have vitiligo]," but they can.
>
> (Elizabeth, Vitiligo)

Because she had already "transitioned," Elizabeth's disease experience was assumed to be "easier" than the experiences of those that she was representing. As a result, she was viewed as less "relatable" than she was when she was transitioning and, because of that, was socially marginalised within the community. Elizabeth self-identifies as a black woman and, during her interview, she discussed the various ways in which her

[37] Melanin is the dark brown pigment found in the eyes, skin, hair etc. that offers protection from harmful rays produced by the sun.
[38] "Transitioning" is used to describe participants who have both depigmented patches and healthy patches of skin. The contrast between the two is often stark, particularly when the original colour is dark, and this often means that patients who are transitioning believe that their disease experience is worse than that of patients who have completely depigmented because they typically attract more attention.

depigmented skin is often mistaken as a sign that she is “Latin” or “Hispanic:”

> My pastor used to make this joke, he goes "let me know how it is when you get on the other side because now that you look like you're white you might get better privileges" [laughs] and I'm like well maybe as long as I don't open my mouth! … I don't think I look white, people more likely take me for Latin or you know Hispanic. You know I go in restaurants and right away they're speaking Spanish and I'm like I don't speak Spanish and they say "you don't speak Spanish?! Why Mami?!" and I'm like please! And my husband is Puerto Rican so [with] the two of us together that just throws them totally off … they’re like "you're not Hispanic?” and I say no I'm not Hispanic so. But I guess when my hair is short then it's a little easier for them to like make that mistake, but once I let the 'fro [afro] grow then they can tell I’m not Hispanic. White no, Spanish yes.
>
> (Elizabeth, Vitiligo)

Elizabeth’s understanding of what it means to be recognised as black despite having visibly “white skin” corresponds with an idea that is commonly discussed amongst critical race theorists that “blackness” can be expressed and communicated through numerous signifiers that do not necessarily centre skin colour (Davis 2001; Wayne 2014). These signifiers commonly include: accent, language, hair texture, phenotype etc. The joke that Elizabeth’s pastor made about her “looking white” and, therefore, having access to “[white] privileges” is funny precisely because she cannot access these privileges as a black woman who continues to “show” her racial identity through her hair, language and accent (“maybe as long as I don’t open my mouth!”).

The use of African-American vernacular to communicate cultural identity amongst blacks in the US is a topic that has been studied at length, particularly in relation to marginalised blacks whose black identity has been rendered “suspect” because of their “non-traditional black upbringing” and/ or because they are viewed as not “looking black.”[39] In their book *Articulate While Black: Barack Obama, Language and Race in the U.S* H. Samy Alim and Geneva Smitherman note that black vernacular was both intentionally and unintentionally used by Obama during both of his presidential campaigns in order to appeal to black voters who questioned his “blackness” as a bi-racial and ivy-league educated senator from Chicago (Alim & Smitherman 2012, pp.1–30). They argue that Obama gained popularity in black communities across the US because he was able to “demonstrate” his blackness through language and intonation. Elizabeth’s suggestion that her “mouth” (i.e. language and mode of speech) conveys her racial identity by clearly showing that she is black demonstrates the same

[39] A “non-traditional black upbringing” in a US context is commonly understood as one that is not directly affected by poverty, poor schooling and/ or inner-city life.

understanding.

The relatively high visibility of vitiligo on blacks when compared with whites means that many people often assume that vitiligo is a "black disease" that is predominantly, if not exclusively, prevalent in this racial group. During their interviews numerous participants would often claim that they too made this assumption, and that it was therefore often surprising when they saw and/ or heard about white people with it. As noted by one black participant: "when I first got it [vitiligo] I thought it was a black disease, I didn't know white people got it and I didn't know Asian people got it … because I never saw anybody white that had it." During her interview one white participant who had completely depigmented noted that whilst she is happy that her disease is now largely invisible because her skin is "all one colour," others routinely mistake her for being "ill" because she "looks pale." This, she claimed, often makes her feel "self-conscious" and "unattractive" when in the company of people with "normal" skin:

> Sometimes I feel terrible about myself when I'm like super pale … people will always say, they'll come up to me - even friends - and be like "oh you look really sick today." Or on the days I don't do any kind of make up and it's just like I look natural so I look pale, really pale, they'll say "you look sick, are you feeling ok?" I'm like yeah [nervous laugh] I'm fine.
>
> (Jessica, vitiligo)[40]

Jessica's awareness of her "sickly" appearance means that she is constantly aware of her disease despite the fact that it cannot be seen by others. Unlike blacks with vitiligo that are often able to pass as "light skinned" or "Hispanic," she is often assumed to be in a permanent state of poor health. Moreover, although her vitiligo cannot be "seen" by others, the presumption that she is "ill" means that she still faces potential stigmatisation from those who assume that her "illness" is contagious.

On occasion, during their interviews vitiligo participants would claim that, despite their visible symptoms, the people with whom they came into contact regularly "failed to see" their disease. This failure, they argued, was largely because they were "confident" in their appearance, which ultimately deflected attention away from their symptoms. As noted by Lauren, a vitiligo participant in her mid-20s who, at the time of the interview, sold cameras in her local camera shop: "after I started selling cameras and working in the professional world I felt like, you know, people just forget about the vitiligo. They don't even see it." Thus, Lauren's customer service and knowledge about the products

[40] Jessica is a white patient who used skin tanner for years to hide her vitiligo. Because her peers were used to seeing her with tanned skin, when she stopped using tanner they viewed her depigmented skin as a sign that she had "lost colour" and was therefore "ill."

that she was selling prevented others from focusing their attention on her vitiligo to the point where, she argues, they "[didn't] see it." This sentiment was echoed by another participant when asked whether or not she was concerned about the reaction that her boss might have to her visible symptoms. Noting that she initially was, this participant later claimed that he responded by saying that her "big" personality would prevent others from seeing her vitiligo, which, for him, meant that it was not an issue: "he [boss] said that I was a big enough person that I would consume it [vitiligo] itself, you know? The vitiligo – no one would see that because I'm such a big person and that's always been how I've projected myself, you know?" For both participants, their personalities and positive interactions with others were seen to preclude any negative attention that they might receive because of their appearance.

Occasionally, AKU patients who are in the early stages of their disease have visible yet discreet symptoms such as facial ochronosis and dark sweat. As I will later discuss in my chapter on passing, it is often possible for these patients to continue to pass as "unaffected" by their condition by concealing these symptoms from public view, either by applying make up or by wearing dark-coloured clothing. As their disease progresses and these symptoms become more visible, patients often express concerns that other people will see them and view them as indicative of a lack of hygiene rather than as signs of a chronic condition. When describing the ochronosis in her sclera during her interview, one patient noted that, because the ochronotic pigment was identical in each eye, she was less troubled by it. This symmetry, she claimed, meant that "no one would really know that anything is wrong or different" about her appearance. As a result, she felt able to pass as "normal" and avoid stigmatisation, which meant that she could remain largely unseen in relation to her condition.

Conclusion: Navigating Stigma and Disease (In)visibility

By way of a conclusion I wish to return to the opening statements of this chapter. For Janet, the relative invisibility of her chronic disease meant that she is often left questioning whether it would be better for others to see her condition, or whether it would be better for it to remain unseen. Both, she argues, would likely result in stigmatisation. If it remains unseen she could be accused of falsely seeking disability benefits without a proper need for them, and if it is seen she will likely be treated differently by others who would then likely recognise her as "disabled." As a result Janet is conflicted: she wants to be seen as someone "worthy" of the disability claims that she is making, but she also wants to be seen as someone who is "normal" in relation to others. Austin's stigmatisation primarily occurs during his interactions with black women. Because they cannot look past the changes that his disease has made to his appearance they cannot "see" him as a person who exists separately from it,

therefore they cannot see him in relation to the way that he sees himself. This, in turn, leaves him feeling "invisible" to them, and causes him to "shape his racial identity" by reconsidering who he is and who he should be affiliated with.

Both accounts offer useful thematic depictions of some of the key challenges that people from both disease groups face on an everyday basis. As this chapter has shown, participants commonly express what they perceive to be the benefits of making their disease known, and the ways in which this often conflicts with their private inclinations to conceal all knowledge of it from the public and pass as "normal." Participants purposefully use badges and other visual signifiers of disease in order to educate others about their condition and demonstrate their confidence in living with it. This, in turn, demonstrates their efforts to subvert the stigmas that they commonly face and turn them into something positive that they can gain strength from. In addition, participants from both disease groups relate shared feelings of alienation and exclusion because others fear that their disease is contagious. Claire's exclusion from her neighbour's annual pool party and Amanda's experience with the customer who hesitated to take money from her hand clearly show the ways in which both participants face rejection from those who fear that they will be "contaminated" by coming into close physical contact with them. Both reactions ultimately result in stigmatisation, wherein both participants are avoided and/ or "feared" because of the "threat" that they supposedly pose to other people.

In their efforts to "control the gaze" participants from both disease groups are often able to gain a modicum of control over how they are seen, which ultimately reduces their chances of experiencing stigmatisation. The more able they are to minimise or deflect attention away from their visible differences the more able they are to pass as "normal" or "unaffected" and, thus, avoid stigmatisation. In a similar way, if participants are able to offer a visual "explanation" for their differences they are less likely to be stigmatised as "deviant" and/ or "unsafe" to be around. Christopher's use of a walking stick to visually signify to others that his affected gait is the result of a disability and not of an alcohol or drug addiction clearly shows this. As I will discuss in the following chapter on passing, it is common for people with vitiligo to wear badges that feature slogans such as "it's just vitiligo, it's not contagious" in order to ease public fears about the possibility of contagion. Their awareness of these fears provokes people with vitiligo to *anticipate* negative reactions to their appearance from others, and consequently drives their decision to either conceal signs of their disease or publically acknowledge it in order to promote awareness of it.

Existing on the Border: Passing, Resistance and Subversion

Race, LGBTQ and disability scholars have long used the term passing to describe people from marginalised groups who intentionally change or manipulate their bodies or behaviour in order to claim identities that are not socially assigned to them at birth (Afshar 2012; Woodward 2015). Typically, these identities belong to dominant social, racial or political groups that are afforded greater privileges because of their higher social, political or economic status (Walker 2001; Dawkins 2012).[41] After they alter their appearance or behaviour, passers are rendered 'invisible' in relation to the identities that they once claimed. Blacks who pass as white are no longer seen as black, gay men and women who pass as heterosexual are no longer viewed as gay, and disabled people who pass as able-bodied are no longer understood to be physically or socially limited (Walker 2001).[42] Passing destabilises identity categories by challenging the assumption that people who look or behave a certain way belong to specific racial, class or gender groups (Ahmed 1999; Pisiak et al. 2018). Because identity categories are socially and politically constructed, they are subject to the shifting contexts in which they are formed and given meaning. What might be considered "feminine" or "masculine" in one context is not necessarily so in another, and one can be simultaneously white and black in different contexts depending on how each racial category is locally defined (Scales-Trent 2001). As argued by Judith Butler, social identities are performative and, thus, exist separately from, and pre-date, the person who enacts or claims them (Butler 2016: 24).

By having physical or behavioural attributes that are typically understood to be "uncharacteristic" of the groups to which they socially "belong," passers destabilise identity categories that are frequently regarded as "fixed" (Brubaker 2015). Passers often arouse suspicion in those who are unable to place the passer within the confines of normative identity categories that often operate within specific binaries (i.e. white/ black, male/ female, able-bodied/ disabled etc.).[43] As noted by Erving Goffman in his work on stigma, people who are able-bodied " expect the cripple to be crippled; to be disabled and helpless: to be inferior to themselves, and they will become suspicious and insecure if the cripple falls short of these expectations" (Goffman 1990, p.110). When a person is ill we expect to see "evidence" of their illness. If they have the flu we expect that their nose will be red and that they will cough

[41] In her work on passing and the connection between different forms of passing (i.e. disability, gender etc.) Lisa Walker argues that all forms of passing are connected in some way to racial passing. She states: "no figure accused of passing could be considered apart from race passing and from the origins of that concept in American culture, where the sexual exploitation black women in slavery and the ongoing practice of miscegenation (re) produced light, but not 'white,' bodies within the black population. In turn, the visibility of any identity group is necessarily linked to the paradigm of racial visibility" (Walker 2001, pp.11–12).

[42] By "socially limited" I mean prevented or discouraged from entering into social spaces and/ or from socially engaging with others.

[43] Here I use the term "normative identity categories" to describe primary identity categories (i.e. race, gender and class) that are often socially assigned to people based on what their bodies seemingly suggest about them (i.e. in relation to skin colour, body shape etc.)

violently, and if they have food poisoning we anticipate that they will vomit consistently throughout the day. Even when their illness cannot be seen we presume that a person's body or behaviour will "show evidence" of it. As I will outline in the following chapter, people who experience chronic pain are often routinely questioned by doctors, family members and peers who doubt that they have this experience because they are unable to see "evidence" of it (Ciribassi & Patil 2016; Ojala et al. 2015). As a result, people with chronic diseases who have learned to cope with and/ or manage their daily experiences of pain and fatigue often feel the need to *perform* their illness in order to "show" this experience to others. This performance is often at odds with their lived experiences of dealing with their disease, however patients routinely view it as necessary in order to legitimise that experience to others who cannot see it and/ or have no way of understanding it. Because their symptoms are chronic, they are often normalised by patients who experience them on an everyday basis (Report 2018; Doran 2014). For AKU patients, as their disease progresses and their chronic pain becomes an "ordinary" feeling that is integrated into their everyday way of being it often becomes more and more difficult to imagine what their life was like before they experienced pain. In this way, their performance of pain serves as a *re-imagining* of what their reaction to that pain might be if it were in any way new or different.

Passing can be both intentional and inadvertent. Whilst it is possible to purposefully alter one's body in order to fit with normative ideas of what one's body "should" look like, it is also possible to inadvertently pass as a member of a "deviant" or stigmatised group without making any bodily alterations (Goffman 1990). As noted by Sara Ahmed in her study of passing, "passing may function at the level of the intentional subject (the subject who seeks to pass in order to secure something otherwise unavailable to them), or it may function as a misrecognition on the part of others (one may pass for something other than one's self-identification but not seek to, or know it)" (Ahmed 1999, p.92). During their interviews, AKU and vitiligo participants both claimed that onlookers frequently mistook their visible symptoms for signs of either personal neglect or deviant behaviour. Several vitiligo participants noted that onlookers typically assumed that their skin had depigmented because of failed attempts at skin bleaching.[44] Some also assumed it to be evidence of that person's involvement in a household fire or related accident. AKU patients who had an affected gait often described instances whereby, because they had chosen not to use a walking stick, their gait was understood by others to be indicative of their drug use and/ or alcohol addiction. As I discussed in the previous chapter on stigma, without their walking stick patients from this disease group often felt that they were being "judged" by others who were unable to see their disability. Because they anticipate these reactions when in public, many AKU patients reported instances in which they would manipulate and/ or modify their appearance in order to hide their affected gaits from other people and pass as "healthy." This was particularly the

[44] Skin bleaching refers to the increasingly common practice of applying an (often harmful) substance to the surface of the skin in order to achieve a lighter skin complexion.

case when patients were in situations where they purposefully sought to make a good first impression (i.e. in job interviews).

In both disease groups, the patient's ability to *choose* when to disclose or hide their condition is a crucial factor in determining their ability and willingness to pass. As I will later discuss, people with vitiligo who are unable to afford cosmetic products that are effective in covering signs of their disease are typically unable to pass successfully. As a result, they are less likely to attempt to pass. In a similar way, AKU patients who are unable to afford the drug Nitisinone are significantly more likely to show signs of their disease as they age and their symptoms progress. Because the Food and Drug Administration (FDA) has not yet licensed Nitisinone for use by AKU patients, most medical insurers do not cover the costs of the drug and doctors are often reluctant to sign a prescription for it.[45] Patients who do not have the financial means to pay for their Nitisinone prescription and/ or who do not personally know of a doctor who is willing to sign their prescription cannot gain access to this drug and, as a result, typically have a worse overall disease experience.[46] Those who are able to access this drug are often successful in concealing noticeable signs of their disease, and are thus typically able to choose if and when to disclose information about their disease to other people. As a result, they are significantly more likely to pass as "healthy" or "unaffected."

In a similar way, US medical insurers invariably do not cover the costs of effective vitiligo treatments that have consistently shown positive results. As previously stated, because vitiligo is medically recognised as a "cosmetic" disease that does not negatively affect the patient's physical health, it is largely viewed as a "non-medical issue" that can and should be individually managed by patients (Al-faresi et al. 2013; Tanioka et al. 2010). The monetary and governmental resources that would be spent in helping these patients would, many argue, be better-spent treating conditions that lead to increased incidences of morbidity (i.e. cancer) (Kaiser 2016). Thus, in both patient groups, the likelihood of the individual passing is largely determined by their social and economic status. Together, both facilitate passing by providing patients with the necessary resources to conceal or effectively manage their disease symptoms in a way that renders them 'invisible' to others.[47]

Whilst vitiligo does not affect the physical health of the person who has it, participants often claimed that onlookers assumed that their appearance was indicative of a "debilitating" health condition such as deafness.[48] As a result, participants were often spoken loudly to or avoided

[45] Doctors are often reluctant to sign a prescription for Nitisinone for use by AKU patients because they worry that prescribing a drug that is not FDA approved could compromise or severely damage their medical reputation and, potentially, career.
[46]In relation to chronic pain and fatigue.
[47] Whilst these symptoms are largely invisible to unsuspecting onlookers, it is possible for medical professionals who have heard of AKU to recognise these symptoms as signs of the condition.
[48] I do not wish to suggest here that deafness is always considered a debilitating condition. Much work has been done to address the advocacy work that has been done by deaf people who do not consider it to be a debilitating or disabling condition, but rather argue that society *makes* it debilitating/ disabling by

altogether when in public environments. As noted by one participant, "I've had people talk louder to me. It's vitiligo, it's skin, it doesn't have anything to do with my hearing but I've had people talk louder to me … and I've had people come up to me and assume it's some kind of disability." Because AKU and vitiligo are both largely unknown diseases it is easy for members of the public to fail to recognise their symptoms as indicative of these diseases.[49] In response, patients often wear and/ or show visible signs that clearly mark them as people who have either disease. Participants typically view this as an act of resistance that allows them to express pride and/ or comfort in having their disease. They also view it as a way to advocate for their condition and generate funding for it. Advocacy, they argue, is key to challenging misconceptions about how their disease affects them on an everyday basis as it allows them to (re)educate people who do not understand what their disease is and/ or how it shapes their lives.

With both conditions, the lack of governmental and/ or federal assistance in disease management strategies means that participants are regularly left to independently manage their disease. As I have noted elsewhere in this thesis, the higher the participant's social and economic status the more likely they are to have access to treatments that will render their disease 'invisible' to onlookers, therefore the more likely they are to pass. In this chapter I will assess the effectiveness of the passing strategies that participants employ in order to mitigate their disease symptoms and render them invisible. I will further consider how participants who choose not to pass utilise resistance strategies in order to generate public awareness of their disease and encourage funding for it. I will conclude by evaluating the effectiveness of these strategies in determining whether or not participants can pass, and the extent to which this is aided or hindered by their social and economic status.

Wearing a Mask/ Being in the Closet

> It felt nice to take the mask [make up] off because when you put the make up on you're hiding behind someone that you're not, and when you're hiding that person you're also hurting that person. So I just felt like I was pretending to be you know like a full caramel person [skin colour] when I'm really not, you know? I have spots on my body and so why should I cover them? And so it took me a really long time to just be like do you know what, I'm not going to spend this extra 20 minutes on my face right now to try and cover up this white spot right here. I'm just going to leave it as it is.

failing to accommodate them. Vitiligo participants who were assumed by others to be deaf, however, viewed it as a disabling condition.

[49] Whilst AKU is medically considered a rare disease vitiligo is not, however vitiligo is often considered "rare" by those who have it who do not regularly come into contact with other people who also have it.

(Lauren, vitiligo)

I never bring it [AKU] up but if somebody asks and is interested I will talk to people about it, you know? I've learned kind of with how people are to kind of keep it quiet if you will, because you get different people just saying different things or not knowing what you're talking about. And like I said what I ran into the other day just little scenarios of that where one person knows a little bit more than another, or they think they know a little bit more than the other, and they don't grasp really what it is but they're like spouting out stuff. So I want the knowledge to be out there but after some comments on messages that I've posted on social media I usually am like ok, I better take this post down now. I'm in the closet, I'm kind of in the closet I feel. Like I feel like I kind of have to hide my AKU. Only if somebody really wants to know do I sit there and tell them about it … like I can understand and relate to people that are like in the closet about anything or everything, I can you know relate to that because it's something I feel like I have to hide. I don't want to hide but I do, you know?

(Claire, AKU)

I remember when, it sounds funny, when I "came out" at church [laughs]. You know like I wore the shorter dress and I had my arms out and we marched for offering at church and I remember carrying my goddaughter and when I got back to my seat and church was over people were like 'oh I didn't know you were sick,' that's when the albino business came in. I finally was like you know what it is too hot for this [long-sleeved clothing to cover vitiligo] and it is too hot for that. This is, you know, me - hello! See me.

(Elizabeth, vitiligo)

These excerpts convey typical reactions from participants from both disease groups who, when asked why they choose to reveal or conceal evidence of, or information about, their disease, claim that their decision originates from experiences that they have had with people who respond negatively to them because of it. For Lauren, efforts that she had previously made to pass by covering her vitiligo with make up made her feel as though she was "pretending" to be someone she is not (i.e. a person without vitiligo). Whilst passing made it possible for her to avoid stares and comments from other people, it also prevented her from expressing who she is in relation to how she sees herself, which had a negative effect on her

mental health. Lauren's decision to remove the "mask" by no longer wearing make up demonstrates a conscious effort to prioritise her mental health above the negative attention that she received from others because of her appearance. By showing her vitiligo-marked skin, Lauren no longer felt that she was "hiding" an identity that she is now able to proudly claim as her own. For Claire, the fear of being misperceived and/ or misunderstood when talking about AKU is a key motivator for concealing all knowledge of it. In order for her to disclose details of her disease she first needs to be invited to do so, and she then only reveals a minimal amount because she fears that the listener will misunderstand what she is saying and will later inaccurately relate the information that she has given them to other people. Knowing that others falsely believe that her disease affects her in ways that it does not causes Claire a great deal of anxiety, and this motivates her to remain "in the closet."

For Elizabeth, her decision to "come out" by showing her vitiligo whilst at church was the result of a practical feeling of being "too hot" in clothes that hid her condition from view. After she revealed her vitiligo she was presumed to be "sick" by other members of the congregation who mistook her symptoms as signs of poor health. She later corrected them by outlining what the disease was, what it meant for her, and how it differed from albinism.[50] The discrepancy between Lauren's view that passing is detrimental to her emotional wellbeing and Claire's view that passing is necessary in order to ensure hers in influenced by the degree to which both are able to *choose* whether or not to pass. Because Lauren's condition is difficult to conceal in all areas of her body it is always immediately visible to onlookers.[51] Moreover, she cannot choose to pass in ways that render her condition wholly invisible, which means that, for her, learning to accept how she looks with vitiligo involves learning to accept how other people see her. For Lauren, this acceptance is key to building resilience against the daily stares and comments that she receives that constantly remind her of her visible differences. Because AKU does not mark her body in any visible way, Claire can choose not to disclose information of it and, thus, can choose to avoid any negative attention that it might bring. Whilst this discrepancy suggests that Claire's ability to choose when to reveal or conceal her disease places her in a favourable position, it also means that, unlike Lauren, Claire has to explain the fact that she has a disease to other people and, in some cases, prove its existence in order to be seen in relation to it.[52] Her silence prevents others from recognising how her everyday symptoms (i.e. chronic pain, dark urine and dark sweat) impact her life in meaningful ways, which makes her feel as though she is "in the closet."

The contention between choosing when to pass and when to disclose is one that is central to all traditional passing narratives. Numerous blacks that passed as white during the Jim Crow era chose to do so at various intervals in order to profit from employment opportunities that

[50] There is a common misconception that vitiligo is directly linked to albinism as both result in a loss of skin pigmentation.
[51] This is, of course, largely dependent on the clothing that she wears.
[52] During her interview Claire described at length how she was often required to prove that she had a medical condition to others who, because they had not heard of AKU, did not believe her.

they otherwise would not have had. Whilst they passed as white at work they often returned to their families and reclaimed their black identities at the end of the day, a phenomenon that passing historian Allyson Hobbs refers to as "working white while living black" (Hobbs 2015). Knowing that they were returning to a space that would allow them to recover their racial identities meant that they were able to withstand many of the psychologically damaging effects of passing. Common effects include experiencing an identity crisis and permanently disowning close friends and family members (Hobbs 2016). On days when they feel particularly conscious of their appearance people with vitiligo often choose to remain in their homes, either by themselves or accompanied by family members. For many, the support of their families and the comfort of being in a familiar space temporarily relieves the burden of "looking different" and allows them to go about their daily lives without being constantly reminded of their disease and the ways in which it makes them "different." In this way, participants are able to pass as "normal"/ unaffected by their condition whilst they are at home. As noted by one participant:

> Everybody would be encouraging me to go out and do things and I'd just be like no, I don't want to do it because I don't want to go out there and have to deal with the stares and the looks and everything. I'm just like so sick and tired of it. I'm like you know what I don't want to. I don't want to deal with that today. I don't want to acknowledge the fact that I have vitiligo and I look different than everyone else, I just want to be inside chilling in the house and watching TV or doing nothing or playing video games. Or you know I'll wait until night time and just go to a movie theatre where everything is dark in there and no one's staring at me because everybody's watching the movie or whatever.
>
> (Anthony, vitiligo)

Anthony's anticipation of the negative responses that his appearance would invite when he entered into public spaces prompted extended periods of social isolation. During this time he would purposefully avoid social spaces in favour of remaining at home where he could, temporarily, forget about his vitiligo. Viewing his home as a safe space, Anthony felt able to carry out everyday activities without being consciously aware of his body and how it "differs." However, unlike Anthony numerous other vitiligo participants who lived with family members often attempted to hide their condition whilst at home by wearing make up to conceal it. Rather than viewing their home as a safe space, these participants understood it as a place that rendered them vulnerable to negative remarks from those who were closest to them. In this way, their attempts to pass whilst at home serve as a recognition of the fact that these spaces are "unsafe" whilst they are in them and make up free. They are viewed as particularly unsafe when people from outside of their immediate family visit their home. During her interview one participant discussed how, when her children were young and had

friends to sleep over at her house, she would go to bed late at night and wake up early in the morning in order to ensure that her children's friends did not see her without make up:

> In my house yeah my family they would see me without make up but … when my kids had other kids stay over or whatever what I would do was I would make sure you know that they were you know fed or they had their little snacks or whatever they needed and after that I would wash my face and stuff and I wouldn't go back out [leave bedroom] no more. So really 9.30/ 10 that was it, I didn't come back out again until the morning. I would get up before they would, I'd get up probably 6 or 7 o'clock before anybody. I'd have been and already took my shower, I'm already completely already dressed and got my make up on and everything. So right now the girls that come over that stay all night with my daughter they be like 'when did your mom's face get like that? I didn't know her face was like that' because I put it [make up] on before they woke up when they were children they never knew I had it [vitiligo].
>
> (Sarah, vitiligo)

When her children did not have visitors Sarah viewed her home as a "safe space" in which she could walk around without make up and not be criticised. Once she got home she would routinely "remove the mask" of make up that she had applied earlier that morning and allow her children to see her with vitiligo. However, when other children visited her home she viewed it as temporarily "unsafe," as these children could potentially criticise her because of her appearance whilst they were there. Fearing this, Sarah kept her make up on when they were in her home until she was sure that they would not see her. In doing so she was able pass as a "normal" when around them, and her success is made evident by the surprise that these children showed years later upon discovering that she had had vitiligo for decades ("they never knew I had it"). On occasion, Sarah would be caught off-guard by the sudden appearance of these children in her home and, because her children had failed to pre-warn her, she would react negatively towards them:

> Sometimes when I came out the living room thinking it was only us [family] in the house some of my kids friends were there and I would, I'm not going to lie, sometimes I would just start yelling and stuff and go back in my room and stuff like that. I'd be like 'why didn't you tell me somebody was in here?!' [aggressive tone] and stuff like that. I'd say 'you see how my face is' and stuff like that so [crying] I think about that stuff. I know they [her own children] understand now you know but when I just look back at it and see myself and the way that I was reacting and the stuff that I said I feel bad because that was probably hurtful for them.

By inviting their friends into the house without warning her, Sarah's children unintentionally exposed her to a type of harm that she only anticipated when she left her house. Unlike Lauren who was able to decide when to make her vitiligo known, Sarah was prevented from deciding whether to "come out" as a person with vitiligo because her children unknowingly made that decision for her when they invited their friends to visit. It was only after Sarah accepted her disease and embraced the changes that it had made to her appearance that she could understand the damaging effects that her aggressive responses had on her children.

Like people with vitiligo, AKU patients often claim that, for them, their homes function as "safe spaces" because they offer protection from disease-related stares and comments. As noted elsewhere in this thesis, because AKU is a rare condition, it is common for people to be unfamiliar with it and to mistake visible symptoms of the disease for signs of other conditions or "deviant" behaviour. Because their gaits are commonly affected, older AKU patients often stumble when in public spaces and, as a result, are often mistaken for alcoholics or drug addicts. As noted by one AKU patient, "I walk like a goofy person, sometimes like a penguin. You might think I'm drunk or you might think [I'm] pretending to walk like this." By remaining at home, patients are often able to avoid these mischaracterisations that invariably lead to stigmatisation (Goffman 1990, p.14).

In addition, AKU patients often view their homes as "safe" because they have practically adapted them to meet their mobility needs. Older patients, in particular, often noted that they purposefully modified their homes in order to meet their current and future mobility needs, and that this relieved some of their concerns about falling and causing further joint damage when they were at home. By equipping their homes to suits their needs, AKU patients are able to temporarily overlook the limitations that their disease imposes on them. Thus, whilst they are at home they feel able to somewhat pass as "healthy" or "able-bodied" because they are free to carry out ordinary tasks with the help of these aids. This is particularly important for patients who are keen to minimise the emotional distress that their spouses and family members experience when witnessing them in pain. During his interview, one patient discussed how he wanted a stair lift so that his wife did not have to see him struggling to get up and down the stairs. Another patient related how she purposefully designed her kitchen so that her husband would not see her struggling whilst she was preparing meals. Thus for both patients, the need that they felt to pass stemmed from their interest in minimising the damaging effects of their condition on those who were closest to them.

It is important to note that, for some patients, their homes do not function as "safe spaces" because they allow others to see "embarrassing" symptoms on a regular basis.

When relating how she dealt with having dark urine as a child one patient noted that she was regularly self-conscious about it, and that this was exacerbated by her mother's negative remarks about the "stains" she would leave on her clothing after urinating:

> I was self-conscious about my urine when I was little because it turns black. Because it turns black I would be very self-conscious about it and so like say one time my mom made a joke but I didn't know it was a joke. I go can I go to the bathroom? And she goes 'no' and I go why not? And she says 'oh because they're working on the sewer down the street' and she makes up this story that anybody who flushes the toilet it's gonna go and everybody's going to see it you know or whatever and they're gonna know it was you because it turns black. And so anyway so I was self-conscious always. So I would like I could hear other people in my house, my mom didn't realise I believed her I guess because I could hear other people in my house going to the bathroom and my brother and my mother and my father they would all go and just go and then leave the room like nothing. They weren't even sneaking. And then I would have to get up early and sneak and go in there and pee. Or go pee outside and then dump water over it.
>
> (Janet, AKU)

The necessity that Janet felt to "sneak" to her bathroom early in the morning was the direct result of the uneasiness that she felt in having other members of her family see her dark urine. Later in the interview Janet discussed the fact that she continues to feel "shame" about having this symptom as a result of these negative remarks, and that this "shame" is linked to her understanding that having dark urine is a sign of "dirtiness" or "uncleanliness." Her attempts to hide evidence of her dark urine from her family members demonstrates a desire to pass as unaffected by this symptom whilst she was at home, which is something that she was often unable to do.

How Patients Pass: Mechanisms and Techniques

When in public, AKU and vitiligo participants employ different strategies in order to pass as "healthy" or unaffected by their condition. Doing so allows them to mitigate and, to an extent, control the amount of attention that their disease symptoms attract.[53] These strategies often involve significant cosmetic and/ or lifestyle alterations, which vary in accordance with the participant's disease stage. The more progressive the participant's symptoms are the more difficult their symptoms are to conceal and, therefore, the less likely they are to successfully

[53] Note that participants are limited in their ability to control the amount of attention that their disease symptoms attract because they cannot control the individual subjectivities of the onlookers who criticize them.

pass. In an effort to prove to family members, doctors and close friends that they are still able to participate in social activities that they enjoyed before their symptoms began to manifest, it is common for AKU patients to physically exert themselves by pushing their bodies beyond what they are physically capable of. This signifies a form of passing as it often only takes place whilst others are looking at them, and involves the patient concealing any evidence of their strain or difficulties in completing the task. Typically, these patients are aware that they will likely experience an increase in joint pain the following day, which will likely leave them temporarily bed-ridden. However, for them, this pain is a small price to pay for the feeling of accomplishment that they will get after completing these activities. This is particularly the case when the patient views the activity as a central component of their identity. Engaging in these activities means that they are able to retain a sense of who they are by continuing to do what they enjoy. Additionally, it allows them to feel somewhat in control of a disease that continuously threatens to erode their capacity to "be themselves" in relation to how they self-identify.

During her interview one AKU patient who was diagnosed with kidney stones (a common AKU symptom) claimed that, after she underwent surgery to remove them, she "carried on as normal" by riding her horse the same day: "I went in to the hospital, got a stent taken out, they put me under anaesthetic and broke up the stone, put another stent in and I was riding my horse that afternoon at four o'clock." Determined to maintain her daily routine and show her peers at her local riding stable that she was "fine," this patient purposefully pushed her body beyond its limit in order to minimise the impact that her disease had on her lifestyle. By riding her horse the same day as her surgery, this patient was able to claim a semblance of normality whilst in the company of her peers by passing as physically capable when, at that moment, she was not. The pain that she endured as a result of pushing her body beyond its limit was, for her, worth the satisfaction of knowing that she was able to participate in an activity that she had always enjoyed.

Because vitiligo is a "cosmetic disease," the participants that I spoke with were not concerned about the physical costs of over-exertion when attempting to pass as "healthy" or unaffected. However, participants routinely expressed concerns about the emotional costs of concealing their disease with clothing or make up, and the negative long-term effects that this had on their mental health. During their interviews, numerous participants discussed having experienced prolonged periods of depression as a result of failed attempts to conceal evidence of their disease and pass as "normal." Many knew of other people with vitiligo who had attempted suicide because of their disease-related mental health issues. These participants would often discuss their concerns about the long-term impact of this emotional strain, and the ways in which they felt that it negatively affected their physical health. They would also often relate their frustration with what seemed to them to be futile attempts to conceal a disease that not only changed their appearance, but was also psychologically detrimental. As argued by one participant:

> You can't cover up something that's not just physical but [also] psychological. It's kind of like having a secret, no one knows when you have a secret of something that happened to you that you don't want anyone to know, now you have something that's so pronounced in the room that people see. You can't hide it.
>
> (Michelle, vitiligo)

For Michelle, even if she was successful in concealing her vitiligo and passing as "normal," the psychological affects of the disease render it impossible to hide. Dark-skinned vitiligo participants are particularly vulnerable to everyday forms of negative attention and discrimination because the disease is significantly more visible on them than it is on white or light-skinned patients. As noted in my chapter on stigma, black people with vitiligo who have completely depigmented often inadvertently pass as "light-skinned" or Hispanic when in public, and white people with vitiligo often pass as "naturally pale skinned."[54] For dark-skinned people who have not completely depigmented, however, their disease is immediately visible to others when it covers areas such as their face, neck and hands.[55] White people with vitiligo have the additional advantage of being able to conceal their depigmented skin and regain a semblance of their "normal" appearance by applying mainstream tanning products that are readily available in drug stores. These products make the white depigmented person appear "naturally tanned" and "healthy" after they have applied them, and in doing so allow that person to pass as "normal." As noted by one white patient:

> Once it [vitiligo] pretty much took over my body I started wearing tanner … I wear tanner now because I'm like all one colour again [completely depigmented]. And so wearing tanner is pretty much like I'm free again like from everything. And I remember the first day I was wearing full tanner and I actually went into the little downtown area in my city and no one stared at me! And I was like oh my God I'm wearing an invisibility cloak right now, like no one can see me! This is so cool! I was so freaking excited I was like this is what it's like to be a normal person, this is amazing!
>
> (Vanessa, vitiligo)

For Vanessa, wearing tanner means that she is able to socialise in public spaces without being seen in relation to her condition. The invisibility that she is afforded because of this product means that she feels "free" when in these spaces, and is uninhibited by the stares and comments that often came before she depigmented. Because their skin colour is typically

[54] Depigmentation occurs when people with vitiligo are completely devoid of pigment i.e. when they show no remaining evidence of their original skin colour.
[55] Participants reported feeling particularly self-conscious when their vitiligo spread to these areas because they are immediately visible to onlookers.

darker than the mainstream tanning products that Vanessa uses, black/ dark-skinned people with this condition are not afforded this type of opportunity to become "invisible." During her interview Vanessa acknowledged this difference by noting that, because they cannot conceal evidence of their disease by artificially tanning, black/ dark-skinned people with vitiligo are more likely to seek relief by openly communicating with other people about their disease:

> Pretty much every white girl I've talked to tries to hide it [vitiligo], and that's like their go to way of coping with it. African-American people just like they have to talk about it. Like there's not really another choice, they can't really hide it the way lighter skinned people can. And I've often noticed that because of that there seems to be like a racial divide within the vitiligo community … I do think that there is just, I don't know, there's like a cultural difference about how you approach it. And I just get that feeling because like when you start meeting different pockets of people with vitiligo black people are always grouped together and like white people are always grouped together.

According to Vanessa, racial divisions within the vitiligo community are the result of a mutual understanding of the ways in which this disease affects different groups in different ways. She infers that, because black people presumably share an understanding of what it means to live with this condition, they are naturally more inclined to socialise with other black people in the vitiligo community. In a similar way, because they too presumably share similar experiences, white people with vitiligo are more likely to socialise with each other at vitiligo events and community meetings. Thus, by interacting with other people from the same racial group, people with vitiligo feel more able to share their experiences of living with it and exchange information about cosmetic products that are particularly suited to their skin tone.

People with vitiligo who do not have white patches on areas of their body that are immediately visible to onlookers (such as their face or hands) are often able to pass as "normal" by wearing clothing that conceals affected areas of skin. Clothing that conceals these areas can be perceived as either intentional or inadvertent acts of passing depending on the individual circumstances surrounding the wearers choice of garment. It is often difficult to equivocally state whether a person with vitiligo who wears concealment clothing does so with the intention of passing or whether they pass unintentionally. A person who has visibly depigmented patches of skin on their arm might purposefully wear long-sleeved shirts in order to conceal this from public view, or they might choose to wear them simply to stay warm. Whilst the former is premeditated, the latter is unintentional and does not demonstrate a purposeful attempt to pass as someone who does not have vitiligo. AKU patients often relate feelings of embarrassment and/ or shame when evidence of dark sweat and/ or dark urine is detected on their clothing. As previously stated, others often mistake both as evidence of a lack of hygiene rather than as symptoms of a genetic condition. As a result, many patients purposefully choose to wear dark clothing in order to minimise the

visibility of these symptoms. Additionally, AKU patients often regularly replace their clothing when the dark stains become difficult to wash out. As noted by one patient:

> When I was working we used to, the dress style was coat and tie and it was generally white shirts, and while the shirt was not worn out I would have to replace them sooner than I otherwise would have to. Because under the arms and around the neck it had a tinge on it, you know from the sweat. And they you know you can also see for example if we don't replace the pillows frequently enough, that even you know just sleeping and drooling and whatever else goes on when you're sleeping it's the same thing. And so I know that all of my bodily fluids are dark and will stain and so forth so I don't wear white underwear, just coloured underwear. I tend to wear more like this [points to shirt], this blue shirt and things like that so you really can't see what's going on. And so I mean you know it's just, I've accommodated myself. I don't wear any sort of white or light coloured pants because as guys do they sometimes don't completely clean up after they urinate and so as a result you know instantly it stains. And if it's a shirt tail then you can tuck it in but if it's pants you know you get maybe 5 or 6 uses of them and then you have to throw them away and start over again with another pair.
>
> (James, AKU)

James's ability to pass as "healthy" or "unaffected" by his disease is made possible by his ability to minimise the visibility of his dark sweat and urine by wearing dark-coloured clothing. Before he retired James was a lawyer, and whilst working in his office he was obliged to wear white shirts that quickly made these symptoms visible. In order to conceal his symptoms from other people, he had to frequently replace them with new white shirts that were not yet stained. Additionally, at the time of the interview, James purposefully chose to buy dark-coloured pants that did not show dark-coloured sweat and urine stains. Whilst his reasoning suggests that this necessity is gendered ("as guys do they sometimes don't completely clean up after they urinate"), during their interviews female AKU patients also often discussed purposefully choosing clothing that minimised the visibility of their symptoms:

> I wear a lot of black clothes. In my closet I have a lot, I wear maroon and black a lot. Maybe I'm being self-conscious because I'm a girl, I don't know. But yeah I mean a lot of my shirts for exercising and stuff are darker. The ones that aren't darker they turn a lot quicker you know underneath the arms and in the neck where I sweat. So that's kind of embarrassing. And then I throw them away, white shirts I wear a couple of times then throw away. Unless I'm on Nitisinone, then they last a little longer. But it's just part of the AKU, right?

(Claire, AKU)

For Claire and James, routinely replacing their clothing is a way of ensuring that their disease remains hidden from others, allowing them to pass as "normal" or "unaffected" by their condition. However, it is important to remember that AKU patients are only able to regularly replace their clothing if they have the financial means to do so. Patients who are unemployed and/ or financially dependent on the state are typically unable to regularly buy new clothing, which prevents them from concealing evidence of their disease in this way. For many patients who do not have the financial means to replace their clothing, their stained clothing functions as a constant reminder of their disease and its symptoms. Despite being able to attribute the stains to symptoms of a medical condition that they are unable to control, these patients are often made to feel personally responsible for them, which causes many to think of them as indicative of their "dirtiness" and/ or "uncleanliness." As noted by Janet who, at the time of the interview, was unemployed and waiting to hear the outcome of her application for disability benefits:

> When you have AKU you think oh well you're kind of different. You're dirty [and] you have all this stuff that's gross and your urine smells more than other peoples' and your sweat leaves dark marks. Because I can't afford new underwear I'm stuck with the same bras and they always show the marks.
>
> (Janet, AKU)

Because Janet could not afford to replace her clothing, which showed visible signs of her dark sweat, she was constantly aware of it in a way that patients like Claire and James who could afford to regularly replace their clothing were not. In other words, due to her relative poverty, Janet was unable to pass as "normal" in the same way that they could because her dark sweat remained visible. However, when asked about her attempts to conceal some of her other disease symptoms Janet responded by saying that her affected gait often went unnoticed when she was in public spaces if she was with her dog. The dog, she claimed, would often become the sole point of focus and would thus draw other people's attention away from her "bad" posture, rendering her visible differences "invisible." That, combined with the physical stability that her shopping cart gave her when she was shopping for groceries, enabled her to pass as "normal" when in public spaces such as her local supermarket:

> If I have the dog with me the dog is so cute that everybody goes 'oh look at the dog' and I think she's like a good buffer, you know? I can push the cart at the grocery market, I can push the cart and I don't look like anything's wrong. That's why I think I need a walker that's up here [gestures high], because if I just [peers over top of imaginary cart] around the market I don't look any different. It might

> be you're just going and following the cart and then my dog is right there and they'll look at her and not me.
>
> (Janet, AKU)

By deflecting attention away from her bodily differences, both her dog and the cart allow Janet to pass as "normal" and, thus, lessen her self-consciousness about being seen in relation to her symptoms and her condition.

Performative Identities: Subversive Performances

> The hope of those who try to pass is that no one will have anything different to say about them. Passing compels one to blend in, to be the same, to be normal … Although people with disabilities may try to pass in the classic sense of the term by concealing their disability from discovery, they also engage in a little discussed practice, structurally akin to passing but not identical to it, in which they disguise one kind of disability with another or display their disability by exaggerating it. This practice clouds the legibility of passing, and it is sufficiently different from traditional passing both to merit a closer look and to invite its own terminology … I refer to these altered forms of disability passing as the 'masquerade.'
>
> (Siebers 2004)

In the above statement Tobin Siebers argues that there are two key ways for people who have bodies that look "different" to effectively manage their "differences" in order to render them "invisible" in social and local settings. The first way is passing, which he notes is employed by those who purposefully choose to conceal their visible differences in order to subscribe to socially regulated norms that govern how one's body "should look" (Featherstone 2010; Tiidenberg & Gómez Cruz 2015). The second way, the "masquerade," describes a practice employed by those with "abnormalities" who *perform* or *exaggerate* their visible differences in order to draw attention to them. In doing so they seek to emphasise their visible differences for the purposes of social and/ or political gain, thereby using this practice as a form of subversion.[56] Using himself as an example to explain this phenomenon in his introduction, Siebers discusses his experiences in an airport when attempting to board a plane early because of his disability:

[56] "Subversion" is a term that is used to describe the undermining of the power, control or authority of an established system or institution.

> In December, 1999, I had an altercation at the San Francisco airport with a gatekeeper for Northwest Airlines, who demanded that I use a wheelchair if I wanted to claim the early-boarding option. *He did not want to accept that I was disabled unless my status was validated by a highly visible prop like a wheelchair.* In the years since I have begun to feel the effects of postpolio, my practice has been to board planes immediately after the first-class passengers so that I do not have to navigate crowded aisles on wobbly legs. I answered the gatekeeper that I would be in a wheelchair soon enough, but that it was my decision, not his, when I began to use one. He eventually let me board and then chased after me as an afterthought to apologise. The incident was trivial in many ways, but *I have now adopted the habit of exaggerating my limp whenever I board planes*.
>
> (Siebers 2004, p.1, own emphasis)

Because he did not use a wheelchair when he was boarding the plane, the gatekeeper failed to recognise Siebers's disability, which, in turn, led him to question whether or not Siebers was telling the truth about his condition. Needing a visual signifier (such as a wheelchair) to "prove" the fact that he is disabled, the gatekeeper initially attempted to prevent Siebers from boarding early. Despite acknowledging that this incident was "trivial in many ways," Siebers notes that after it took place he "adopted the habit of exaggerating [his] limp" when boarding planes in order to avoid this type of confrontation in the future. By "exaggerating" his limp, Siebers made sure that his disability was made known to others who otherwise would not have seen it. In doing so, he put himself in a position whereby he was easily able to reap the benefits that he was entitled to as a disabled person who could not board a plane with the same ease as an able-bodied person. By enacting a *performance* of disability in order to make his disability known, Siebers demonstrates an inauthentic representation of how his disability affects him on an everyday basis for personal gain. Although he was entitled to the benefits that he was later given, he was only able to claim them by enacting a performance of disability.

Drawing a comparison between passing and the masquerade, Siebers argues that whilst passing "preserves social hierarchies because it assumes that individuals want to rise above their present social station" in order to assume the position of the dominant group, the masquerade "represents an alternative method of managing social stigma through disguise, one relying not on the imitation of a dominant social role but on the assumption of an identity marked as stigmatised, marginal, or inferior" (Siebers 2004, p.5). Both necessitate the enactment of a performance that is at least partially disingenuous, yet they differ in that one involves the concealment of stigmatised differences whilst the other involves an exaggeration of them. Siebers claims that, for those whose visible differences render their identities ambivalent, the masquerade facilitates public ease and acceptance by allowing onlookers to

identify the broader significance of their visible difference(s) and classify them accordingly. Citing an example of a deaf man who, when chastised by a security guard at a museum for seemingly failing to follow instructions reflected that he should have purposefully worn a red hearing aid in order to make his deafness known, Siebers argues that this man "feels compelled to out himself as disabled so that able-bodied people will not be confused, which guarantees at the same time that he will be rendered invisible" (Siebers 2004, p.6). This invisibility, Siebers argues, stems from the disassociation that the deaf man feels from the "performance of deafness" that he is compelled to enact in order to make his condition known.

Thus, the masquerade is simultaneously advantageous for those who enact it because it allows others to recognise their disability and the ways in which they struggle with it, and disadvantageous because it does not allow those who feel compelled to perform to accurately convey their lived experiences of having their disability. Expanding on Siebers's conceptualisation of the 'masquerade' as a form of passing, in her work on feminist theory and female sexuality Lisa Walker outlines the ways in which numerous oppressed groups openly show or exaggerate their visible differences in order to challenge pre-conceived ideas about how people "should look" in accordance with the various identities that they claim (Walker 2001). Using black radicalism and gay pride as examples, Walker notes that "[t]aking their cue from the strategies of groups such as the Black Power movement, whose slogan 'Black Is Beautiful' redefines the symbolic value of skin colour by reversing Eurocentric definitions of beauty, lesbians and gays have adopted visibility politics as one way of refusing the cultural imperative to assimilate" (Walker 2001, p.1). For lesbians and gays, she argues, resistance to assimilation comes in the form of purposefully using visibility politics as a means through which to explore what it means to "look" like you are from a marginalised group.

Walker later goes on to use drag as an example of a quintessential performance of queer visibility. She argues that by exaggerating stereotypical tropes of "queerness," drag artists subvert normative gender identities by outwardly challenging and critiquing common conceptions about what it means to "look like" a man or a woman (Walker 2001, p.1). In a similar way, by deliberately showing their visible difference(s) to others, the masquerading subject is able to challenge preceding norms of bodily appearance by using their body to expose the inherent contradictions and inaccuracies of these norms. By forcing people to look at their visible differences by pointedly revealing them, masquerading subjects are given the opportunity to "look back" at the viewer and challenge their understanding of what their bodily differences suggest about them (Garland-Thomson 2009). As I discussed in my preceding chapter about stigma, this opportunity is often viewed as important for both AKU patients and people with vitiligo as it allows them to (re)establish autonomy in this interaction by (re)claiming the gaze and, where possible, educating the onlooker about their disease.

Concealing visible "abnormalities" from public view allows participants from both disease groups to avoid stigmatising labels and pass as "normal" and/ or able-bodied. Passing, however, is often significantly difficult for participants whose visible difference(s) affect large areas of their body. People with vitiligo who choose to conceal their white patches face numerous practical challenges in covering areas of their body that are in regular use throughout the day, such as their hands. During their interviews numerous participants related their frustrations when attempting to conceal their disease with make up, only to have that make up rub off every time they washed their hands or touched an object. As noted by one participant: "what I hate is like going to the gym, trying to play basketball, and like having make up on. Then you know you're guarding other people [in basketball] and there'll be a brown spot on your leg where you wiped it. If you sweat and you throw it [ball] on the ground there's a brown spot on the ground, you know? Who's going to deal with that?"

In a similar way, AKU patients who have noticeable ochronosis on their hands, face and sclera are often unable to conceal these symptoms because doing so is impractical. Whilst several of the people that I spoke with said that they would use make up to cover facial ochronosis if they developed it in the future, many of them also said that they would avoid doing this because it would likely "rub off" during the day. Whilst most of the participants that I interviewed from both disease groups discussed attempts that they had previously made in the past to conceal visible signs of their disease, most patients conveyed resistance to this idea at the time of the interview. At the time of their interviews many AKU patients were in their late 50s/ early 60s. As noted in the previous chapter on stigma, for many patients this means that they often felt able to attribute noticeable signs of their disease (i.e. their affected gait) to common signs of ageing. Doing this also enabled patients to draw comparisons between themselves and their peers, many of whom also experienced joint pain and a loss of mobility as they aged and their symptoms progressed. By drawing a comparison between how they look and how their peers look, patients felt less isolated and stigmatised because of their condition. Moreover, because they were able to discuss symptoms such as chronic pain with friends and family members who were of a similar age, patients often related feeling "normal" in relation to their condition. As a result, these patients did not typically feel the need to "pass" when amongst their peers.

All of the participants that I interviewed with vitiligo chose not to conceal their disease by using cosmetics or clothing at the time of the interview. Several went into detailed discussions about the products that they had used in the past, and all described the reasons why they chose to stop concealing their vitiligo later on. Common reasons included feeling that it was no longer needed because they had accepted "who they were" in relation to their appearance, feeling as though concealing their disease would mean hiding "who they were" in relation to their appearance, and wanting others with the condition to see that it was possible to lead a "full and happy life" with it. Most of these participants had had vitiligo for over 10 years and, by the time of the interview, the changes that it had made to their appearance were extensive.

As a result, participants grew accustomed to seeing themselves with vitiligo and began to view it as an integral part of how they ordinarily looked. According to these participants, concealing their vitiligo would mean giving a disingenuous performance of "sameness" for the sole purpose of "fitting in," which would, potentially, negatively affect their mental health and well-being. As noted by one participant when asked why she decided to stop wearing make up, "because I am a genuine person and I was kind of being a hypocrite. If you're a genuine person and you're trying to hide yourself from the world by wearing make up, that's not being a genuine person."

When asked how their disease affects their life on a day-to-day basis, participants with vitiligo would often argue that they are "more than their disease." By this they meant that they have other attributes and characteristics that are central to their identity and unrelated to vitiligo, therefore they do not see themselves solely in relation to it. Often, they would simultaneously claim that, whilst they are "more than their disease" their disease was a key part of their identity that shaped them and their experiences by making them "unique." When asked if she was hopeful that there would one day be a cure for vitiligo, one participant related how she felt that she was "chosen" to have this disease and that it made her "special." Another discussed how she felt that vitiligo had given her a "purpose" in life as an advocate and a mentor for others with the condition. This feeling, she argued, developed with age: "I guess since I joined the group, the vitiligo group, that you know I feel like I have a purpose and I have a calling. I'm meant to educate you know people about vitiligo and be an advocate … my purpose has changed since I've gotten older."

Many described the contention between feeling both "more than their disease" and that their disease was a key part of them by outlining the ways in which they would often forget that they have the disease when they are alone, only to be reminded that they do have it when around other people. They forgot it because they did not primarily view themselves in relation to it, and they were reminded of it when onlookers immediately recognised it, responded to it, and were then unable to look past it. Because these onlookers would routinely stare and make negative remarks about their appearance, participants often learned to develop a "thick skin" whilst in public. Typically, this would involve "claiming" their vitiligo by celebrating the ways in which it made them "unique" or "special" rather than focusing on the ways in which it made them "different." By doing so many felt able to minimise the negative impact that disparaging comments about their appearance had on their mental health and self-esteem. As noted by one participant:

> I've got a thicker skin because of my experiences with other people … you never know when I'm embarrassed or what I'm going through. We [people with vitiligo] have to live all day like we don't know what's going to happen to us when we leave our house, you know what I mean?

(Austin, vitiligo)

Because his vitiligo is extensive and therefore cannot be easily covered by cosmetic products or clothing Austin is unable to pass effectively as someone who does not have the condition. As a result, he feels compelled to put on a "front" when in the company of others to mask the negative ways in which their stares and comments affect him (Goffman 1959). To not do so would render him more vulnerable to these attacks when in the company of others as it would allow for them to see, and potentially draw on, his internalisation of their comments. In this way, the "front" that he performs when in their company is a way for him to and potentially minimise his emotional reaction to the negative stares and comments that he anticipates from others. In addition, it enables him to "save face" when around them by not showing any outward signs of "weakness."

Figure 3

The above photograph shows a person with vitiligo modelling a baseball cap that is part of a clothing line called "viti-wear viti-nation," which was designed by a person with vitiligo in order to promote self-esteem and self-worth in those who also have vitiligo and are ashamed of it. With a bold and confident expression on his face, the model looks directly at the camera with his depigmented skin in full view. The visibility of his condition is exaggerated by the stark contrast between his dark and depigmented areas of skin. His cap, featuring the phrase "Viti-King," is worn with pride, demonstrating his confidence in showing off his skin to the viewer. In seeking to challenge the negative comments that his appearance likely attracts on an everyday basis, this cap, coupled with the model's confidence, subverts the common conception that having vitiligo is something to be ashamed of. In labelling himself a "King" because of his condition, this model rejects the view that his skin is a signifier of "ugliness" in favour of the view that it makes him "unique." Moreover, by publically revealing what his disease is and what it means to him, this cap seeks to *emphasise* his vitiligo by making it even

more visible than it already was, and in this way can be seen as an enactment of Siebers's "masquerade."

By visibly evoking and exaggerating their visible differences, participants from both disease groups are able to promote awareness of their disease and advocate on the behalf of others in their disease group who are disempowered and/ or inhibited because of it. When asked, advocates from both disease groups often argue that they seek to highlight the ways in which their condition affects them personally in order to deflect attention away from those who have it and who are particularly vulnerable. This typically includes children and people who do not have the financial resources to seek treatments that will improve their disease's symptoms.[57] AKU patient advocates often circulate photographs taken during surgeries of their damaged joints to researchers and medical professionals who are committed to learning more about AKU and finding a cure for it. They do so in order to increase the chances of subsequent generations developing the disease and suffering with its symptoms as they had.

Because AKU and vitiligo are largely unknown diseases, it is easy for onlookers to misinterpret their symptoms as signs of other health conditions or accidents that they perceive to be related (i.e. MS or albinism). In anticipation of this response, participants often wore signs that visibly marked them as having AKU or vitiligo with the hope of educating others who make this mistake. For vitiligo participants, these signs typically come in the form of badges that reassure onlookers that their disease is not contagious. These badges commonly include statements such as "if you can wear your tattoos, I can wear my skin" and seek to highlight the fact that this particular disease is not contagious. For many participants, wearing these badges allows them to resist the often immediate assumption that they should be "pitied" for having vitiligo because it is "disfiguring." By comparing their disease to elective forms of skin modification (i.e. tattoos), these participants signal the fact that, for many, having vitiligo is a cosmetic marker of uniqueness rather than a stigmatising signifier of difference.

As previously stated in my chapter on stigma, in an effort to increase awareness about the prevalence of diseases that are largely invisible, AKU patients often display stickers on their car that include phrases such as "not every disease is visible" to make their disability known. By displaying them on their car, patients hope to avoid confrontation when publically parking in areas that are purposefully reserved for disabled motorists. Although they do not directly state what their condition is or what their symptoms are, these stickers provide AKU patients with a degree of autonomy by purposefully revealing their disability status to unsuspecting onlookers. By providing visual clarification and confirmation of the true nature of both diseases, these signs allow patients to correct misperceptions that often result in

[57] These treatment options include light therapy, skin grafts and holistic treatments for vitiligo and Nitisinone for AKU.

stigmatisation. They also offer patients the opportunity to proudly claim their disease in public, thus rendering passing an unnecessary practice.

Racial Passing

As noted in the introduction, whilst passing is often used as a generalizable term to describe the act of appropriating and/ or adopting an identity that one is not socially given at birth, it has historically been used to describe blacks who passed as white in order to circumvent legal practices of discrimination. As noted by passing historian Gayle Wald, as a "socially and historically embedded practice" passing "remains defined by the now-you-see-it, now-you-don't contingencies of blackness" (Wald 2018, pp.x–xi). Historically, in the US blacks that were able to pass as white did so for reasons that were often directly related to social and economic advancement. Legally mandated rules and de facto agreements concerning black employment, housing and education typically prevented blacks from gaining access to any form of social or financial capital during the Jim Crow era. Therefore, passing as white was viewed by many who were able to do so as the only means through which they were able to access this type of capital. During the slave era, being light-skinned enough to pass as white also often meant that one was more likely to gain access to freedom (Bodenhorn 2015; Sanders 2011). Because light-skinned/ mixed race slaves were most often the children of their white slave owners or white acquaintances of their owners, they were more likely to be freed after their owner's death, and were more likely to have access to material benefits such as land and property (Bodenhorn 2015; Bodenhorn et al. 2018).

As the children of both their white owners and their black slave mothers, mixed-race slaves not only provoked moral outrage in those who feared racial mixing, but also instigated widespread panic about the possibility of being both white *and* black in a society that insisted that the two were mutually exclusive.[58] As noted in the introduction, many now view passing as white as "passé" because they believe it to be irrelevant in societies that supposedly afford equal legal and social rights to all regardless of their racial or ethnic origin (Bonilla-Silva 2006). In addition, many light-skinned blacks who might have formerly passed now argue that they are unable to pass because their phenotypic features supposedly mark them as "black." These features typically include their nose shape, body shape and hair texture (Davis 2001).

[58] After miscegenation was recognised as a national issue of social and political importance it was legally mandated that children follow the status of their mothers, which meant that any children born to female slaves were automatically considered slaves despite their father's status.

Numerous scholars have used vitiligo as a case study to document the psychosocial affects of "becoming white" for black patients who have the condition (Martin 2002; Papadopoulos et al. 1999; Thomas 2007; Porter 1984). These scholars commonly conclude that this transition is devastating for black people because skin colour is widely viewed as a key marker of racial difference (Porter & Beuf 1991). Thus, losing one's skin colour presumably threatens and/ or destablises the black person's sense of belonging within their racial group. A study conducted by Judith Porter and Ann Beuf in 1991 concerning racial variation in response to vitiligo is perhaps the most notable and widely cited study that directly deals with this issue. Both authors claim that "[s]kin colour is an important marker of racial identity," therefore it is particularly distressing for black people who have it (Porter and Beauf: 1991, 200).

One of the participants that I interviewed, Amanda, is an African-American woman in her early 50s who was diagnosed with vitiligo when she was 28 years old. At the time of the interview her condition had visibly spread to her face, arms and hands and she did not wear any make up to conceal it. Since her diagnosis, Amanda has struggled with depression and anxiety. She married her husband shortly before she was diagnosed, and he later divorced her after her vitiligo began to spread and her appearance changed. During the interview Amanda related how he had repeatedly expressed concerns throughout their marriage about the possibility of her passing on the condition to any children that they might one day have. When she was in her mid-forties Amanda worked as a sales assistant in a gas station close to where she lived. This job involved routine interactions with strangers on a daily basis, many of whom stared at her and made negative comments about her appearance. Amanda's vitiligo had steadily progressed since her diagnosis, and during the interview I asked her whether she had even been concerned about one day fully depigmenting and being mistaken for white. She responded by recounting an incident that took place between her and a customer's young son who, upon seeing her, assumed that she would be "happy" when she was one day "white." Her response is worth quoting at length:

> A: I was working at the gas station and you know he [white child] was looking at me and his parents were shopping around the store and he kind of kept standing there looking at me. And he came up to me and came around the side where I was standing and tapped me and said "won't you be happy when you become a white person?" That's what he said. And I was like wow, and it's a child so you have to keep that in mind when you're talking to people. I was like er no and he was like "well, why not?" so he took the conversation you know [laughs] much further than I was willing to take the conversation. And I'd say he was maybe 7 or 9, somewhere in there. And at first when I talk to kids about vitiligo I will just say God touched me and made me special. That's always my answer because you can't go into the medical reasons for vitiligo with a child, they're not going to

understand. So I said that to him and that still wasn't enough of an answer, you know? So then when his parents came up to the counter he's like "look she's turning into a white person!" And you know the mother of course was really embarrassed and the father couldn't have cared less what he was saying you know so. It really, that bothered me. It really kind of upset me, you know? Because no [I don't want to be white], if I had the choice I'd want my brown back, you know? I just do, I've been a black person for 53 years and if I totally depigment I'm still going to be a black person. That doesn't change you know, right? [Question aimed at me]. [I nod] Yeah that doesn't change [sounds assured]. So I was offended, I really was. I was very upset by that.

T: Do you think that if you completely depigmented people would look at you and see a black woman?

A: Yes [nods]

T: Why do you think that?

A: My features, you know? My little round nose and I wouldn't say fuller lips but my hair and then you know my ethnicity, the things that black people do. I'm going to be in the beauty supply shop [laughs] you know and I'll be shopping for lipstick and you know finger nail polish. I'm still going to go to the Black Expo [local black health fair] and I'm still going to you know be a Prince fan until the day I die [laughs]. There are just certain things that as black people we do and so that probably will never change for me. I love being a black person!

Several points are interesting to note about Amanda's response. Firstly, the child's reaction to her appearance clearly shows that, for some, her vitiligo can be mistaken for a sign that she is gradually "turning white." When Amanda contradicts the child by offering the explanation that she typically gives to children (that "God touched [her] and made [her] special") he does not believe her. For him, her white skin visually signifies that she is becoming a white person. Moreover, he views her attempts to "become white" as natural. For him, it is understandable that Amanda would want to "become white" because he views being white as better than being black. It is this that Amanda finds particularly distressing, as it means that she is inadvertently complicit in the continuation of racist ideas that mark being white as "superior."

Knowing that he interpreted her vitiligo as evidence that she would be "happy" once she "became white," Amanda reacted negatively when recounting this incident during the interview. Moreover, she responded by repeatedly defending her identity as a black woman. She sought to "prove" that he was wrong by listing all of the behavioural characteristics that she believes mark her as a black woman including her consumption

of cosmetic products, attending local events that are specifically designed for black residents, and listening to Prince. These characteristics, she argues, are intimately tied to her ethnicity as an African-American woman and cannot be threatened or eroded by her changing skin colour. As a result of these characteristics, she will remain a black woman even if all of her skin depigments. It is also interesting to note that the child's mother "was really embarrassed" by her son's comments and, presumably, made attempts to silence him. In doing so she conveyed her awareness that Amanda's appearance was the result of a medical condition, and was not in any way related to a change in her racial identity. Finally, it is important to note that Amanda directed the question of whether she would still be black if she completely depigmented at me ("I'm still going to be a black person. That doesn't change you know, right?"). In doing so she sought reassurance from me that she would remain black even after she lost her skin pigment, which, in turn, suggests that she was not entirely certain that she would. After I nodded in encouragement, Amanda seemed reassured and reaffirmed this sentiment: "Yeah that doesn't change."

On rare occasions when their racial identity is contested because of their appearance, black participants often claim that it is primarily children who question it. Unaware of the fact that their appearance is caused by a medical condition, these children read their skin colour as indicative of their racial identity. In doing so, they automatically assume that because that person is losing their pigment they are "turning white" (Thomas 2007). Whilst having breakfast with three black attendees at the World Vitiligo Day conference in Detroit, one of the attendees with vitiligo related an incident in which her young son mistook her for being white. He was learning about the history of the transatlantic slave trade at school and he assumed that, because she was "white," his mother had also played a role in it. This excerpt from my field notes details her response:

> Whilst we were having breakfast Ellen told me an interesting story about her son. He was at school learning about slavery and when she went to pick him up from school he sat in the car and told her about it and how awful it was. She agreed and said "yes it's awful," and he said "how could you do that?" She was confused and asked him what he meant. He said "how could you do that as a white person?" She then said that she wasn't white and he said "it's ok mom" to pacify her for supposedly committing this crime. She later involved her husband in this discussion at home and she said "I'm black" and her son said "no, you're white." He eventually believed her.
>
> (Field notes, June 2017)

Failing to comprehend the time that had elapsed between the slave era and the present

day, Ellen's son not only mistook his mother for being white but also blamed her for being complicit in the atrocities that took place during the slave era. Maintaining her position as a black woman, Ellen involved her husband in this discussion in order to convince her son that she was not white. Although she related that this was a difficult conversation to have with her son at the time, as she told this story she laughed and dismissed it as an everyday comment that a child would likely make because of her "white" appearance.

As outlined in my thesis introduction and methodology chapter, AKU is a disease that is primarily diagnosed in the US amongst white people. At the time of writing very few people of colour have been diagnosed with it, and no black people are currently known to have it. Interestingly, whilst it is uncommon for white patients to experience extensive ochronosis that darkens their skin to the point where they "look black," during his interview one patient discussed how he knew of a patient in Australia whose skin darkened significantly as a result of having AKU. Because she was frail and thin her blackened tendons and joints were more visible, which made her look "dark coloured:"

> When the lady died in Australia, one of her children felt that it was important for me to send to the NIH the lady's death certificate and so as far as attributing cause of death and so forth so I did. They're going to send me also some pictures of her shortly before she died. Because what happened with her is that as you know all of the connective tissue is dark and black in our body, in an alkaptonuria body. And she was not eating well towards the end so even though she was this petite woman, when we saw her she was maybe 5ft tall the fat in her face and on her body diminished to the point where her skin looked like it was dark coloured, which was really the tendons and stuff being close to the surface of the skin like it is on my hands. You could see that she was you know ill, more the effects of alkaptonuria.
>
> (David, AKU)

For David, this woman's darkened skin was clearly reflective of her illness, and did not in any way signify any type of racial "transition" from white to black. However, as she grew more and more unwell as a result of having AKU, her disease gradually altered her appearance to the point where she had a visibly "dark" complexion. This might have led others who did not know about her condition to question it and/ or to assume that she is not white.

Conclusion

As this chapter has shown, the social and financial means that participants from both disease groups have access to largely determines their ability to access treatments that minimise the visibility of their symptoms. AKU patients who have access to Nitisinone experience a reduction in the accumulation of homogentisic acid, which, in turn, means that they are less likely to suffer from chronic pain and mobility issues later in life.[59] This, in turn, means that they are more likely to pass as "normal" or "unaffected" by their condition than those who do not have access to this drug. In addition, these patients are less likely to require joint replacement surgeries as they age and their symptoms progress. In a similar way, people with vitiligo who are able to afford costly treatments that are not covered by medical insurers are more likely to show signs of repigmentation over the course of their disease (Rodrigues et al. 2017). Effective treatment options often require a financial commitment from patients who are likely to be, at best, only partially subsidised for them by medical insurers. Thus, in both disease groups, the patient's ability to pass is largely dependent on their ability to financially cover the costs of treatments that will minimise their disease's visibility.

Depending on their particular circumstances, patients from both disease groups might choose to pass as "healthy" or "unaffected" by their condition, or they might choose to exaggerate their symptoms by using visual signifiers that clearly point to them (i.e. a walking stick or a t-shirt outlining their condition). The choice that participants make to pass as "normal" or to exaggerate their symptoms is largely dependent on their ability to choose if and when to reveal their condition. For participants who are unable to prevent their symptoms from being seen by others because they either cannot be concealed with cosmetic products and/ or cannot be mitigated by certain drugs, they often feel left with no other choice but to accept the way that they look and the various responses that their symptoms will likely produce in others. Accepting and, in some cases, embracing their disease serves as the only way to effectively deal with it, as it allows them to build the resilience that they need in order to ward off any negative forms of attention and prevent them from internalising it.

The decision that participants make to pass is also largely dependent on their disease stage. If their symptoms have advanced to the point where they can no longer be concealed, participants are unable to easily pass as "healthy" or "unaffected." For many, the masquerade offers an alternative way to deal with their condition and their symptoms as it allows them to subvert typical understandings of what both mean for them in a way that is beneficial to them. By allowing them to mitigate and/ or control how they are seen, the masquerade serves as both an educational tool and as a way of

[59] Note that joint pain derives from a build up of homogentisic acid, which causes ochronotic pigment to form on the patient's bones and joint cartilage, eventually leading to joint and bone deterioration and, often, chronic pain.

reconceptualising how bodies are read in relation to the disease symptoms that shape them. Many who engage in this practice do so with the hope that it will, ultimately, lead to a reduction in the stigmatisation that many people with AKU and vitiligo routinely face. Drawing on some of these conclusions, I will now turn to my chapter on pain in order to show how, as a non-visual signifier of "illness," pain is a useful thematic issue to explore how participants conceptualise their experiences of being seen and/ or unseen in relation to their disease. By arguing that emotional and physical pain are interrelated experiences that cannot be viewed separately from one another, I will show how participants understand their disease through their shared experience of pain. I will further show how this shared experience is often limited by the *performance* of pain that participants feel compelled to enact around other people who are unable to "see" it.

Theorising Pain in Response to Chronic "Illness"

> The pain grew steadily worse and I grew more and more furious because nobody had ever talked about the physical pain. I had thought the emotional and psychological pain would be the worse, but it was the physical pain that seemed to be doing me in … the physical pain was power, for it kept that conscious part of me away from the full flavour of my fear and loss, consuming me, or rather wearing me down for the next two weeks.
>
> (Lorde 1997, p.38)

> I'll never beat the AKU. It's going to win. I can fight to try and minimise its damage but I will never beat it. It's already won in so many ways. It's stolen most of my joints, it's evaporated almost 4 inches of my height. I miss being over 6ft tall, I don't like this 5 ft 10. It's taking my mobility. This is the battle I fight the hardest but I feel it winning. No matter how hard I fight, or how hard I work and exercise it still wins … it's very heavy and depressing knowing it's not going to get better.
>
> (Christopher, AKU)

> If you're going through emotional or some type of psychological aspect of life it makes everything else difficult to do, whether it's physical [or] whether it's financial. Because some people, because of their emotional state, they can't work or they can't work well. They start taking on physical aspects of illnesses and what not because of these things.
>
> (Anthony, vitiligo)

The biomedical claim that emotional and physical pain are inherently separate experiences because they are rooted in a division between mind and body has largely been debunked by academics working in this field (Jackson 2005). The notion that physical and emotional pain are interrelated is now widely accepted, and it is now largely agreed that to draw a distinction between the two prohibits a full understanding of the social and emotional costs of pain. Because pain is rooted in the individual experiences of the sufferer it is always subjectively felt, therefore it is idiosyncratic in nature. As noted by Jean Jackson in her anthropological study of pain and bodies, "the experience of pain is always both 'mind' and 'body,' mental and physical, simply because the pain experience is always embodied" (Jackson 2011, p.373).

People who experience pain often make immediate efforts to alleviate this feeling by using drugs and/ or holistic therapies (Lee 2013). In neoliberal economies such as the US where stoicism is highly valued, one's ability to recover from adversity and re-form one's life accordingly is often understood to be a positive signifier of one's "resilience" (Son Hing 2013; Bracke 2016). In this way, one's ability to recover from pain is understood to be indicative of *personal achievement* because it presumably requires individual "strength" and/ or "courage" from the person who has it.

In his canonical text *The Culture of Pain* David Morris argues that the experience of pain is "shaped by such powerful cultural forces as gender, religion, and social class," and that pain "is reinforced – and sometimes created – by psychological and emotional states such as guilt, fear, anger, grief, and depression" (Morris 1991, p.20). Thus, according to Morris, physical pain is not only influenced by emotional experiences of hurt or trauma but is also formed by them. The "psychological and emotional" states that we find ourselves in can directly cause pain, and both are often linked and/ or "shaped" by our cultural identities. In making this claim Morris argues that our subjective experience of the world determines how we feel pain, and the extent to which we feel it. Morris further argues that some feel pain more acutely than others because how we have come to view and understand pain has been shaped by our social and cultural experiences. Because our responses to pain are culturally and socially specific, Morris claims, it is possible for people from different backgrounds to experience the same pain in different ways. An example of this can be seen when considering the practice of purposefully removing a headscarf from a Muslim woman in public. Whilst most women would object to having a scarf forcibly removed from their head by a stranger, this experience would be significantly more traumatic for a Muslim woman who wears a headscarf for reasons that are directly tied to her religion. Because their emotional responses to this practice would differ the psychological affects that it would have on those two women would likely vary, rendering the Muslim woman more hurt and/ or psychologically disturbed by it (Dorlin 2016).

Research suggests that routine exposure to prejudice or discrimination in the form of racism and/ or sexism can result in processes of ill health that lead to a number of chronic health conditions, including diabetes, heart disease and fibromyalgia (Sullivan 2015). As I will discuss in this chapter, the relationship between physical and emotional pain is made evident through the connection between chronic stress and bodily health. When a person experiences trauma it often manifests *through* their bodies by exacerbating symptoms or spurring the onset of illnesses that were previously unfelt. In a similar way, experiences of illness often cause psychological disturbance in participants who have to monitor their activities and readjust their lives in accordance with their disease symptoms. As previously noted, for vitiligo participants, the visibility of their condition means that they routinely draw attention from onlookers who do not necessarily recognise their depigmented skin as indicative of a medical condition. Assuming their vitiligo to be the result of a burn or their involvement in a

household accident, onlookers often stare or negatively comment on their appearance, which typically induces feelings of shame and mortification in that person who recognises the full extent of their difference. The level at which this shame is felt directly corresponds with that person's ability to deflect negative attention away from themselves and/ or embrace feelings of body positivity. If a participant has accepted their altered appearance and is able to view their body in a positive way they are less likely to feel shame or embarrassment because of their vitiligo. This, in turn, means that they are less likely to suffer from stress as a result of having this condition, which decreases their overall chances of developing other stress-related chronic conditions (Warren-Findlow 2006; Hall 2018).

As I have argued elsewhere, because their disease is not immediately visible, AKU patients do not ordinarily anticipate stares and negative attention from onlookers. Whilst seemingly placing them in a position of privilege, their relative invisibility often means that they must *prove* that they have their disease to others in order to be seen in relation to it. This typically results in a performance of illness that is at odds with how they see themselves in relation to their disease. Because patients often grow accustomed to their chronic symptoms, many of these symptoms, including chronic pain, become a part of their everyday lives and experiences. During their interviews, numerous patients discussed no longer knowing whether or not they were in pain because their pain experience had become "normal" to the point where to *not* feel it would have been unusual. Because their pain is "normalised" in this way it often goes unnoticed by those who fail to recognise it until they experience a *new* pain or sensation. In other words, in order for patients to fully recognise their pain, it must be "distinctive" in a way that renders it different from their ordinary experience of pain. As noted by one patient, "you get used to the pain and you kind of blank it out."

Acute pain experiences can be beneficial. As I will later discuss, academics and medical professionals often note the importance of acute pain in warning us against potential hazards that could threaten our wellbeing and, ultimately, our survival (Melzack & Wall 1996; Morris 1991). When our body comes into contact with a harmful object (for example a radiator) our immediate experience of pain prompts a reflex that draws our body away from the harmful object. This serves to both make us aware of the harm that the object has already caused (we look at the affected area immediately after we remove it and examine any damage caused), and prevent us from incurring further damage by remaining in contact with the harmful object (we instinctively move our bodies away from the harmful object). As a result, medical conditions such as congenital analgesia that prevent the person who has it from feeling pain are often viewed as "dangerous" because they do not allow for this type of warning (Melzack & Wall 1996). Because they cannot feel pain, people who have congenital analgesia are not alert to the danger that painful positions and/ or harmful objects pose, which means that their bodies are constantly at risk of serious injury.[60]

[60] Examples of painful positions or harmful objects include standing or sitting for too long and hot objects (i.e. radiators).

Unlike acute pain, chronic pain serves no purpose. Whilst it can be useful as a symptom that allows medical professionals to diagnose an underlying medical condition that may be causing it, chronic pain does not alert the person who is experiencing it to any immediate threat or danger to their body.[61] This is particularly true for AKU patients who do not fully recognise their chronic pain as *pain* because it has become a "normal" part of their everyday experiences. Because they fail to recognise it in this way, their chronic pain is useless as a felt indicator of the physical damage that their disease is causing. Their *new* pain, however, *is* productive as it alerts them to the fact that further bone and/ or joint deterioration has taken place. By conceptualising new pain in relation to chronic pain, patients often overlook the latter by not viewing it as comparatively painful. Thus, in viewing their chronic pain as "normal" and their new pain as "acute," AKU patients conceptualise their pain experience in accordance with the biomedical model that views acute pain as useful and chronic pain as useless. As I will later discuss in this chapter, this conceptualisation serves to invisibilise their chronic pain by rendering it commonplace.

As I have noted elsewhere, because it is medically labelled a "cosmetic disease" vitiligo is not understood to negatively affect the subject's health or cause physical pain. However, in this chapter I will argue that the emotional costs of vitiligo often causes subjects to develop conditions that directly cause physical pain, such as lupus and fibromyalgia. In this way, I will suggest that there is an indirect connection between the emotional stress that vitiligo often causes and the physical pain that results from subsequent diseases. I will also note responses from participants who claim that vitiligo directly causes joint pain despite their awareness of the fact that, as a "cosmetic" disease, it should not. Finally, I will discuss how physical trauma to the body (i.e. surgery or tattoos) often either spurs the onset of vitiligo symptoms or exacerbates pre-existing ones. Citing examples from a number of participants who claimed that their disease was "brought on" or "made worse" by incidents involving some type of physical trauma, I will discuss how the participant's vulnerability and/ or precarity increased the chances of them experiencing this trauma and, therefore, increased their chances of them developing vitiligo.

In detailing experiences of emotional pain I will refer to the anxiety that participants from both disease groups expressed when discussing encounters with others who misread their symptoms as signs of "deviance." I will further relate how this anxiety and anticipation negatively affected their overall health in relation to their felt experiences of pain. By drawing attention to the correlations between physical and emotional pain I will argue that these two forms of pain cannot be seen as mutually exclusive experiences, but rather must be seen as mutually implicative. Although chronic pain is normalised by AKU patients who understand it as an everyday mode of being, this experience often induces feelings of depression in patients

[61] Note that chronic pain is often pathologised as a separate or distinct medical condition that exists independently from other medical conditions.

who are unable to continue with pursuits and activities that they had previously enjoyed. Patients who feel that it is necessary to reform their lives and reimagine their futures because of their chronic pain also typically experience bouts of depression, which is worsened by their awareness of the fact that their pain will likely worsen as their symptoms progress. In a similar way, vitiligo participants often related a significant decline in their mental health as their disease progressed and their symptoms worsened. This, in turn, often spurred periods of self-neglect, which negatively affected their physical health.

This chapter will be divided into three sections. Each will relate the affective responses that participants from both disease groups often give to questions related to their overall experience of living with chronic pain. The first will consider whether or not pain can be affectively communicated to others by calling attention to Elaine Scarry's notion that pain "destroys" language, rendering it incommunicable (Scarry 1985). By comparing this claim with the accounts of AKU and vitiligo participants who stressed the need to at least attempt to communicate their pain to others, I will call attention to my own positionality as a researcher who does not have either condition in order to explore how that potentially influenced my interpretation of their pain experiences. I will also discuss other modes of communication that participants used in order to convey their pain experiences to medical professionals and interested researchers, and the barriers that they faced in doing so. The second section will focus on bodily responses to physical trauma and how that is mitigated and/ or exacerbated by experiences of emotional pain. I will draw particular attention to how emotional pain induces physical pain and vice versa, and how symptomatic responses to bodily trauma influence the patient's overall disease experience.

In the third section I will discuss the ways in which participants related *performing* their pain in order to make it either known or unknown to others. For AKU patients, this performance typically entailed an exaggerated display of pain in their doctor's office in order to get a prescription for pain medication. Without this exaggerated performance, many argued, their request for this medication would likely have been denied by doctors who were often unfamiliar with AKU and/ or did not recognise chronic pain as one of its symptoms. As a result, these doctors would often assume that patients were "unnecessarily seeking" pain medication for recreational use, which would often result in the patient feeling stigmatized by cynical doctors. For vitiligo participants, this performance often took place through mediums that enabled them to explore and re-articulate constructed notions of what it means to be "beautiful" (i.e. photography). Collectively, these sections will draw attention to the ways in which participants from both disease groups related their experiences of pain, and how that typically resulted in feelings of social and/ or political (in)visibility in relation to their disease symptoms and everyday experiences.

The (In)Communicability of Pain

In the introduction to her seminal work *The Body in Pain: The Making and Unmaking of the World* Elaine Scarry argues that physical pain is an inherently incommunicable ontology that cannot be felt or understood by anyone other than the person who is experiencing it. She claims that physical pain "does not simply resist language but actively destroys it, bringing about an immediate reversion to a state anterior to language, to the sounds and cries a human being makes before language is learned" (Scarry 1985, p.4). Thus, according to Scarry, the incommunicability of pain is the direct result of our inability to express that pain.[62] When we express pain, she argues, we do so in a way that does not make sense to other people. We make "sounds and cries" that are incommunicable because they have no inherent meaning, and this prevents us from relaying our experiences to other people. Moreover, because pain experiences cannot be effectively communicated, there is no way of measuring our pain in relation to the pain that others experience. Whilst a friend and I might decide to get the exact same part of our ear pierced there is no way of knowing if the pain that we experience is identical. It might even be that one of us experiences a great deal of pain whilst the other experiences little or no pain at all. This is because pain is an inherently subjective experience that is felt and responded to by different people in different ways, which prevents it from being described and classified in monolithic terms (Melzack & Wall 1996; Tait & Chibnall 2014).

Scarry further argues that, despite being within close physical proximity to a person who is in pain, because we cannot know their pain and what their feeling of being in pain means to them at that moment we exist separately from them. Because we are unable to share our pain experiences with other people they are inherently private, and can result in feelings of isolation and invisibility for the subject who must bear the brunt of that experience alone and without any outside recognition of it. Scarry states, "[pain] achieves its aversiveness in part by bringing about, even within the radius of several feet, this absolute split between one's sense of one's own reality and the reality of other persons" (Scarry 1985, p.4). Thus, for Scarry, experiencing pain means living in a "reality" that cannot be shared by other people because the latter's "reality" does not (and cannot) include the same experience of pain. Even though the person in pain might express their pain to the person next to them by gesturing or making sounds that are known to suggest it (i.e. shrieks and groans) we are unable to access or recognise that person's pain in the fullest degree to which it is felt because it is an inherently private experience. Yet despite this, physical objects that are socially and culturally understood to directly inflict pain are often successful in producing affective responses from audiences who, because of those objects, recognise the gravity of the pain that is felt by the person who is experiencing it. Cinematic representations of torture instruments often effectively communicate excruciating pain to audiences who witness it without feeling it. This

[62] Note that here Scarry is specifically referring to physical pain. In contrast to the argument that I am making, Scarry separates physical and emotional pain.

is because audiences are able to *imagine* what that pain might feel like, which sufficiently communicates it.

In this way, whilst the *specific* experience of pain that the torture victim feels when he or she is being tortured is incommunicable, an overarching recognition of the severity of the victim's pain is understood when material objects that are known to inflict pain are made visible. In the fifth instalment of the *Mission Impossible* film franchise (*Mission: Impossible - Rogue Nation*) (McQuarrie, 2015) the lead character, Ethan Hunt, is repeatedly subjected to episodes of torture that temporarily immobilise him. In one particular scene Ethan is shown tied at the wrists facing his torturer (ominously called "The Bone Doctor") whilst the latter carefully opens a suitcase that contains a series of large sharp medical instruments. The camera's focus momentarily lingers on these instruments and then pans out to include the torturer, who shows little concern about using these instruments to inflict harm on Ethan. Moments later the torturer removes the heaviest looking object from the suitcase and places it pointedly on the table. The camera zooms in on the instrument as it falls, and the loud sound that it makes when it comes into contact with the table reverberates across the room. This sound informs the audience that the object is heavy and will cause a great deal of damage if used to physically harm Ethan. The audience does not need to *feel* the pain that this object will inflict in order to *know* that Ethan will experience excruciating pain if it is used to torture him. They are able to gage the severity of the pain that Ethan will feel if struck by this object because they can see and hear how large and heavy the object is.

Communicating pain through visual mediums and/ or objects that are known to inflict pain is most affective when relating *acute* pain experiences. In seeing the heavy object that will be used to harm Ethan the audience consider the *immediate* damage that it will cause, rather than the long-term effects of that damage. Unlike acute pain, chronic pain is difficult to visually relate or signify. The consistency and invariability of this type of pain means that, for those who have it, it often becomes "normal," "everyday" or "routine" (Howden 2008; Sanders et al. 2002). As a result, for those who have had chronic pain for a number of years it often becomes difficult to remember what it feels like to *not* experience pain (Sanders et al. 2002; Howden 2008). During their interviews numerous AKU patients claimed that they often find it difficult to describe their pain to other people because they have gradually become accustomed to it and, therefore, do not recognise it as "different." The normality of their pain experience prevents them from communicating or articulating their experience of it. As noted by one patient:

> I've had to deal with it [pain] for so long that now I'm used to it for the most part. So it has to be a unique or specific or different pain to get my attention because the normal everyday pain has just become routine. Like most recently I went through a different kind of pain where my vertebrae started to collapse. Because like several of my vertebrae spontaneously fused and I've never had back surgery

> so they fused on their own. Because when the disk material goes away and the bones lay on top of each other they eventually just fuse together so that's common throughout my entire spine … but when the disk material collapses and they're bone on bone that's the most pain that they ever create. So I can tell when one's getting ready to fuse or once everything's evaporated because that's when I start feeling that pain.
>
> (Luke, AKU)

Because Luke's experience of pain is on-going it is only noticeable to him when it feels "different," which only happens when it is acutely felt somewhere new. Thus, for Luke, pain is a feeling that arises in response to a new or unprecedented injury; because he is "used" to having chronic pain he no longer feels it in a noticeable way unless he can compare it with new forms of pain. These new pains serve as a warning that the particular bone or joint that is hurting is quickly deteriorating and will soon require medical attention. By self-monitoring his bodily deterioration in accordance with his acute pain levels, Luke is able to recognise his need for medical care as and when it is required. In this way, his acute pain serves a productive purpose by acting as a precautionary sign of joint and/ or bone deterioration (Jackson 2011; Melzack & Wall 1996).

During their interviews participants from both disease groups often discussed attempts that they had made to relate their pain to interested audiences through a variety of oral and written mediums, including: written poetry, spoken-word poetry, diary entries, sketches and blog posts. Those who used these mediums claimed that not only are they effective in educating others about the nature of their disease and their affective responses to it, but that they also provide useful outlets for them to vent their frustration at doctors and medical practitioners who often either failed to understand, or did not believe, that they were in pain. This failure to understand or disbelief often left participants feeling invisible to them in terms of their on-going suffering and day-to-day struggles in dealing with their pain. After her interview one AKU patient who also has multiple sclerosis (hereafter MS) sent me a photograph of a diagram that she drew before a doctor's appointment in order to communicate her symptoms to her doctor:

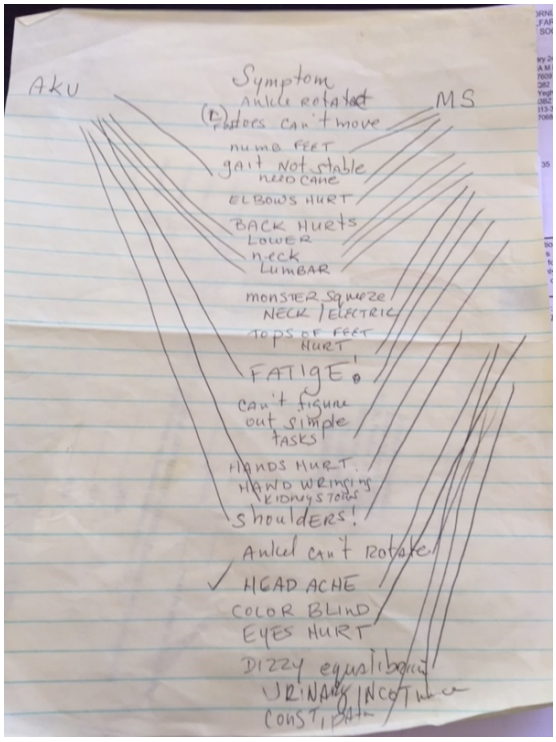

Figure 4

This image shows a series of symptoms that regularly disrupt this patient's life in numerous ways. Some of the symptoms are cognitive ("can't figure out simple tasks," "color blind") but most are pain related ("elbows hurt," "back hurts," "tops of feet hurt," "eyes hurt," "headache"). Because the patient typically feels many of these symptoms simultaneously, it is often difficult for her to mentally attribute specific symptoms to either of her conditions. Drawing them provided her with a way to effectively do this, and offered what seemed at the time to be a useful way of showing her doctor how she understood and conceptualised each of her symptoms. However, when she presented this drawing to her doctors they did not want to see it, and routinely "hand[ed] it back" to her:

> I've brought it [drawing] to every doctor's appointment for a year and a half, or not a year and a half probably 9 months. And for the past 9 months I've brought it and nobody cares, they go "oh what's the matter with you?" and I hand them my paper and they hand it back. You know they go "ok well we don't have to talk about the 1,000 things but what about this?" whatever's the big thing. If one of my legs is cramping we'll just stick with that. And then when it is, well it still is the fatigue. Let's go with fatigue and it's a major complaint here. But you can't have 10 problems or even 3, they want 1 problem per visit [laughs]. Per visit you can't lay a bunch of crap on them.
>
> (Janet, AKU)

By noting that "you can't have 10 problems or even 3" because doctors "want 1 problem

per visit," this patient conveys both the brevity of her doctor's visits and the inadequate medical care that she has received from them. For her, their rejection of her drawing signifies a rejection of her understanding of how both diseases negatively affect her life. Moreover, by rejecting her drawing in favor of their own "expertise," these doctors show their dominance within a setting that confirms and reiterates the process of medicalisation that renders the patient "dependent" on the doctor for their medical knowledge (Foucault 2003; Lupton 1997). During their interviews vitiligo participants would often relate similar experiences with medical professionals who either failed to take their experiences of "suffering" because of their condition seriously, or felt that they knew more about their "suffering" because of their medical training.[63] One participant discussed how she attributes the joint pain that she has experienced from the age of 30 to her vitiligo despite knowing that this link has not been medically proven. Citing a number of examples from her friends who also experience both, she argued that the two have to be linked "for it to be happening to everybody:"

> It [vitiligo] makes me worry about my health because I have a lot of aches and everything and I feel like my body has started aching since like really young, 35 and stuff like that or really 30 … I think actually my bones have kind of like always cracked and stuff, which the more that I do talk to other vitiligo people it seems like they struggle with their joints and everything hurting and aching and I said I think that has you know it has to be connected with our vitiligo for it to be happening to you know everybody, for it to be like that … When I go to the doctor you know I've told them for so long about my hips and everything aching and they don't do anything [sceptical tone]. They pretty much tell you to take Advil and just rub your legs … they don't assist you with that.
>
> (Sarah, vitiligo)

For Sarah, vitiligo is not just a "cosmetic" disease; it is also a disease that causes "a lot of aches" in her joints, which makes her "worry about [her overall] health." Because others who also have vitiligo relate similar pains Sarah feels confident in connecting her joint pain to her vitiligo ("it has to be connected with our vitiligo for it to be happening to you know everybody"). However, when she visits her doctor to discuss this pain they respond by telling her that she should take Advil (an over-the-counter pain relief drug) and rub her legs, which Sarah understands as not "do[ing] anything." As a result, Sarah is left feeling ignored and unseen by her doctor, and feels that it is necessary to independently find a solution for this on-going problem.

[63] Participants often reported that the primary reason why their difficulties in living with vitiligo were not take seriously by doctors was because their doctors viewed it as a "cosmetic disease" that did not cause any physical pain or discomfort.

By showing how the pain experiences of both participants cannot be shared with their doctors, both examples suggest that pain is an inherently private experience that is incommunicable. Whilst others are able to understand one's pain on a conceptual level, they cannot share the same felt experience of it and, therefore, cannot fully understand it, which potentially influences how pain treatment is administered (Ojala et al. 2015). If doctors are unable to understand the full extent of their patient's pain it is possible for them to prescribe a lower dosage of pain medication than is needed and/ or potentially prescribe the wrong medication (Werner & Malterud 2003; Melzack & Wall 1996; Charon 2006).[64] However, in their work on the communicability of pain Giummarra et al. argue that pain can be shared by another person by "resonating with [that person's] emotional state through affect sharing and/ or empathic concern" (Giummarra et al. 2016, p.356). The authors argue that, because we are able to empathise with the person who experiences pain, we are able to recognise their pain and, thus, can connect with it. Moreover, they claim that witnessing incidents of pain "actually brings about the experience of explicitly painful vicarious sensations" in the person who is not in pain, producing an "embodied *feeling* of pain for another" that allows that pain to be felt (Giummarra et al. 2016, p.356). In this way individual pain experiences can be communicated to another person despite that person not actually feeling them, which suggests that those experiences are not inherently private but are, potentially, widely felt.

As I was interviewing participants from both disease groups about their experiences of pain I was struck by my inability to access that feeling despite their vivid descriptions of it. As they were describing their pain, AKU patients would often attempt to relate how they were feeling at that moment by using emotive language that seemingly suggested it, i.e. "throbbing" or "pulsing." Yet this language was ineffective in communicating their lived experience of pain to me as someone who does not also share that experience, and was only useful in providing me with a conceptual understanding of their pain that rendered it abstract/ theoretical. In her work on pain Sara Ahmed concurs with Giummarra et al. by noting that others who witness a person in pain can feel it without personally experiencing it. Using her mother's experience of pain as an example, Ahmed describes how, by witnessing her mother's pain, she was able to "see" it and consequently "feel" it despite the fact that it was "unfeelable" to all but her mother:

> [T]he experience of living with my mother was an experience of living with her pain, as pain was such a significant part of her life. I would look at her and see her pain. I was the witness towards whom her pleas would be addressed, although her pleas would not simply be a call for action (sometimes there would be nothing for me to do). Her pleas would sometimes just be for me to bear witness, to recognise her pain. Through such witnessing, I would grant her pain the status of an event, a happening in the world, rather than just the 'something'

[64] This is not to suggest that all doctors knowingly do this or that they lack the ability to empathise with their patients who are in pain.

> she felt, the 'something' that would come and go with her coming and going. Through witnessing, I would give her pain a life outside the fragile borders of her vulnerable and much loved body … Through being with her, through being so attached to her, I felt the unfeelable.
>
> (Ahmed 2002, p.23)

For Ahmed, the close emotional connection that she shared with her mother, combined with her daily "witnessing" of her mother's pain, meant that she was also a part of her mother's pain experience. By "grant[ing] her pain the status of an event, a happening in the world, rather than just the 'something' she felt," Ahmed was actively involved in the process of making this pain known, which allowed her to feel "the unfeelable." Reflecting on my conversations with numerous participants who unsuccessfully tried to communicate their pain experiences to me, it is possible that my inability to understand and relate to their pain was the result of us not having this shared connection. Whilst numerous participants from both disease groups discussed how their spouses and close family members often failed to understand their experiences of pain and the ways in which it limited them, many claimed that those who were closest to them were typically the most empathetic towards them. As a result, they were significantly more likely to ease their daily burden of coping with it.[65] This suggests that, in order to "feel" another's pain, one is required to have an emotional connection to them that *allows* for that feeling, which does not necessarily require a similar lived experience of it.

Bodily Responses to Physical and Emotional Trauma

> Any kind of trauma that's done to your skin then in that place that color's gone, your color's not coming back … I had surgery in 2004 and where I had the surgery that skin depigmented. It's so bad, I remember thinking oh that means it's healing but no that means your color went away [laughs]! And everywhere that I had that surgery the color was gone, so trauma causes it. Trauma to your skin and stress … stress makes it [skin color] go away as well. My daughter went through a divorce a couple of years ago and that was the summer that the color of my abdomen went away … it's just seemed to happen overnight. I mean I remember just waking up thinking what the heck happened, you know? I was looking at my abdomen going what has happened? What went on? And it was just like overnight it was gone. So stress caused it, you know because I was feeling for her, I was hurting for her. I hate to see her hurt. That was hard and so my body told it.

[65] For example by assisting them in the shower or when getting dressed, or by providing emotional support when they felt anxious about entering into public spaces.

(Linda, vitiligo)

> When I had my son I had an emergency hysterectomy and I had 9 transfusions on the table, they [doctors] really thought I was going to go die. And that was the other thing they thought may have had something to do with this alkaptonuria too, that this was just a horrific delivery. But we didn't know that I had it [AKU] at the time, we didn't know that that's what it was … if there's any stress on your body it [AKU] tends to start to manifest itself …. I basically think that probably was the symptom trigger, when I had my son. And they really were surprised that I lived, he was going to be fine but I had terrible terrible problems, I mean the transfusions alone were just outrageous and they could not figure out why it wouldn't stop bleeding. They cut off an artery! I mean it was just, it was a C-Section that went awry. But in retrospect people think that may have had something to do with the alkaptonuria, there was just something that wasn't working properly at that time and my body was under a lot of stress and that's when it starts to manifest itself.

(Ruth, AKU)

These excerpts describe two cases in which the participant's disease symptoms were directly triggered by unrelated physical and/ or emotional incidents of trauma. The surgery that Linda underwent for an unrelated medical condition triggered the onset of her vitiligo, which eventually spread to different parts of her body, including her abdomen. Initially mistaking her depigmented skin as a sign that her body was healing post-surgery, Linda soon discovered that the loss of pigmentation was a permanent response to the trauma that she had undergone as a result of having the procedure. The additional emotional trauma involved in witnessing her daughter's pain as she was going through a divorce made Linda "hurt," which caused her vitiligo to spread further. Thus, the cumulative affects of the physical and emotional trauma that Linda experienced over a short period of time directly caused the onset, and later the exacerbation, of her vitiligo symptoms. In other words, her "body told" what she was feeling by making her emotional and physical distress visible. Much like Ahmed's ability to "feel" her mother's pain by witnessing her suffering, Linda's ability to "feel" her daughter's pain suggests that it is an experience that can be shared between mother and daughter.

Prior to the delivery of Ruth's first child she did not experience any pain-related AKU symptoms.[66] She and her husband had been trying to conceive for eight years, and were only

[66] Ruth did, however, experience other AKU symptoms such as dark urine, earwax and skin pigmentation.

successful after a number of unsuccessful IVF attempts.[67] At the beginning of her interview Ruth discussed at length her belief that the ochronotic pigment that was later discovered on her fallopian tubes caused her infertility, claiming "my [fallopian] tubes were not supple, they were very dry and brittle … and that had something to do with the alkaptonuria." Despite not knowing that she had AKU at the time, Ruth symptoms had already manifested and had progressed to the point where they affected her reproductive health. In this way, the emotional pain that Ruth felt during an eight-year cycle of trying and failing to conceive was the result of the damage the her disease had already caused. After she finally fell pregnant Ruth experienced numerous complications during labour, which she also attributes to her AKU. The blood loss that she sustained during labour caused her doctors to fear for her life ("they [doctors] really thought I was going to go die"), and the emergency hysterectomy that she had to undergo shortly afterwards meant that she was unable to have more children in the future. Thus, not only did AKU cause her a significant amount of emotional distress in the years leading up to the pregnancy, but it also caused her a great deal of angst in the years following it. By triggering the onset of her AKU symptoms, Ruth's labour spurred numerous bouts of disease-related joint pain, which she felt intermittently for years until she was able to manage her pain by taking Nitisinone.[68]

For both Linda and Ruth, the emotional and physical pain involved in childbearing and childrearing is intimately tied to the emotional costs of motherhood (Stern & Bruschweiler-Stern 1998). Linda's affective response to her daughter's pain was made visible to others through her vitiligo, which continued to steadily progress over subsequent years.[69] Ruth's initial inability to conceive, as well as her subsequent complications during labour, triggered the early onset of symptoms of a disease that, up until that point, had remained largely dormant. In this way, their experiences of looking after and giving birth to their children respectively marked their bodies in significant and permanent ways that would continue to affect their physical and emotional wellbeing in proceeding years.

During their interviews participants from both disease groups often discussed how the emotional costs of having their disease affected their mental and physical health. For vitiligo participants, the demeaning and reductive stares that they often received from onlookers typically led to feelings of shame and/ or embarrassment, which then often lead to prolonged periods of social isolation and self-neglect. In addition, these stares often left participants feeling "unseen" in relation to characteristics that marked who they were before the onset of their disease. For many, this feeling was instinctive and arose before they were fully aware of the ways in which their body and appearance differed from the "norm." During his interview

[67] In vitro fertilization (IVF) is a medical technique that is available to assist those who have fertility problems in having a child.
[68] Taking Nitisinone significantly reduced Ruth's pain by decreasing the build up of homogentisic acid in her body. This significantly reduced the amount of endogenous ochronosis that she had and, ultimately, reduced the deterioration in her joints.
[69] At the time of the interview Linda's vitiligo had spread to a number of visible areas on her body, including her face, neck, arms and hands.

one participant related how, as a young child with vitiligo, he would purposefully choose to play by himself because he instinctively knew that other children perceived him as "different" and did not want to play with him:

> I used to play in a big old hole and pretend like I had a lot of friends with me but it was just me. I used to sit in this big hole all day long from sun up to sun down and I was in there playing by myself. I trusted only a few people, and then when I started getting older that's when you know somebody would actually point out that I was different.
>
> (Austin, vitiligo)

By noting that he routinely isolated himself *before* he was told that he was "different," Austin shows how his awareness of his "difference" was intuitively felt. Knowing that others perceived him in a negative way because of his appearance, Austin sat by himself and "pretended" that he had a lot of friends playing with him in the "big old hole" that he had dug. In doing so he purposefully chose not to interact with others, which rendered him "unseen" in the wider community that he resided in. Later in his interview Austin described the difficulties that he faced in finding a romantic partner because of his vitiligo. He claimed that black women, in particular, did not want to form lasting attachments to him or be seen with him in public because, to them, he looked like a "monster." As I discussed in my chapter on stigma, Austin found this particularly difficult because, as a black man, he understood it to signify a rejection from his "own people." Moreover, growing up in a small segregated town in rural Georgia, Austin's decision to socially and romantically isolate himself from his "people" effectively meant that he isolated himself from everyone, including family members and close family friends.

As a result of being subjected to routine exclusion and discrimination, many people with vitiligo report experiencing suicidal thoughts at various points during their life times. As they see their appearance slowly changing (sometimes beyond the point of recognition) feelings of anxiety and hopelessness often overwhelm their everyday sense of being, which can cause depression and suicidal inclinations. During their interviews participants who were not born with vitiligo often noted that, as their disease steadily progressed, their appearance gradually became "alien" to them. As noted by one participant: "I feel like I'm changing. When I look in the mirror I don't see me, I don't see the ageing me. I see someone that I don't recognise." Because their appearance is at odds with the way that they formerly saw themselves, people with this condition can look in the mirror and not recognise the person staring back at them. Moreover, the psychological disturbance that this causes can leave them feeling as though they do not know their own body. Moreover, because they are often unable to predict how their vitiligo will change on a day-to-day basis, they are often left feeling as though they cannot trust their body to offer a stable reflection of who they are. As noted by another

participant: “I forget I have it [vitiligo] and then I walk past the mirror and I’m like [gasps]! Who is that woman? You know, because I’m changing constantly.”

As well as increasing rates of morbidity in participants who, because of their vitiligo, take their own life, the psychological disturbance that vitiligo often causes can lead to the onset of medical conditions (or the exacerbation of pre-existing conditions) that significantly affect that person’s day-to-day life. When asked during her interview if she thought of her vitiligo as a health concern, one participant responded by stating that she did because it was likely to negatively affect other health behaviours that would subsequently lead to poor health:

> Vitiligo becomes psychological, which can cause stress and that can cause a flare up of lupus, which can throw your diabetes off. Because if you’re stressed or crying or devastated you may not eat well or you may not sleep well. There are different factors to consider having one or more of these diseases.
>
> (Michelle, vitiligo)

For Michelle, the emotional toll that vitiligo takes and the impact that it has on that person’s body is a clear example of the link between emotional and physical wellbeing. The stress that vitiligo causes can lead to periods of self-neglect in the form of food and sleep deprivation, which could, potentially, negatively influence any underlying medical conditions that they might have. If the person with vitiligo experiences stress as a result of having the condition they are more likely to experience these health issues, which means that they are less likely to be able to work. As a result, they might lose their health insurance and other benefits that are given to them by their employers, and they will likely struggle to purchase nutritious food and other necessities that are typically expensive yet necessary in order to maintain good health (Wrigley 2002; Smith Maguire 2018; Winne 2009). The physiological effects of vitiligo-induced stress, and the ways in which it influences employment prospects, was a common concern that participants raised during their interviews. In his discussion about “wellness,” one participant related his belief that different forms of “wellness” (i.e. social, physical, financial) are interconnected, and, in doing so, outlined the ways in which mental and physical health coincide in relation to overall well-being:

> For someone to be healthy I would say there’s an emotional wellness, there’s a psychological wellness, there’s a financial wellness. Not only the social and economic wellness but there’s also a physical wellness … you know financial health is a very big component of the physical health, because if you can’t afford just basic necessities and food and everything to supplement that healthier lifestyle with regards to eating and what not you’ll be unhealthy. Or even if you can’t get medications and different things like that your you know picture of ideal wellness diminishes, you know? … If you’re going through emotional or some

> type of psychological aspect of life it makes everything else difficult to do, whether it's physical or whether it's financial. Because some people, because of their emotional state, they can't work or they can't work well. They start taking on the physical aspects of illnesses and what not because of these things.
>
> (Anthony, vitiligo)

Anthony's assertion that emotional pain is physically limiting calls attention to the ways in which both are interconnected. Not only is vitiligo a mental and physical health issue, it is also, according to Anthony, an issue that is directly tied to "financial health." If a person with vitiligo who suffers negative health consequences because of it cannot afford to maintain a healthy diet or purchase the medication that they need in order to recover from, or manage, other health issues, their overall health will likely diminish.

The connection that Anthony makes between physical, mental and financial health also resonates with the experiences of AKU patients who, during their interviews, often discuss their concerns about not being able to gain employment because of the physical limitations of their disease and the toll that it takes on their mental health. At the time of her interview one patient, Amy, was unable to work and single, and was consequently dependent on state benefits to pay for her rent, food and household bills. Her inability to work, she argued, directly caused acute periods of anxiety as well as chronic depression, which further exacerbated her disease symptoms by making everyday activities "more tiresome" and "more difficult to manage." She described how she was in a constant state of "grieving" for the life that she could have had if she did not have AKU:

> I kept thinking well I'll get this operation done and I can get back to work but there was always another op [operation]. Because I had like most years I had 1 surgery if not 2, and then between that and the fatigue and the pain I haven't worked since. And so I'm kind of grieving for what would have been [starts crying]
>
> (Amy, AKU)

For Amy, the relentless and exhaustive task of having a series of joint replacement surgeries within a short space of time meant that she was no longer able to work. As a result, she entered into a state of mourning in which she "grieved" for the employment opportunities and the life opportunities that she might have missed because of her AKU. Later in the interview Amy described how the cumulative effects of the medication that she was taking for her depression and her AKU caused her thyroid to become overactive. This, in turn, meant that her behaviour became erratic and

unpredictable, which caused tensions between her and her daughter who worried about the effects of this behaviour on Amy's financial and emotional stability. In response, her daughter privately sought advice from Amy's doctor without informing Amy. During their meeting her daughter and doctor discussed Amy's turbulent mood swings and "uncharacteristic" spending habits (she had recently purchased an expensive bed and a Bluetooth speaker) and decided that an intervention was necessary. This intervention came in the form of a local team of mental health professionals entering her home and keeping her under constant surveillance for two months. Feeling as though she had lost control over her life, Amy confronted her daughter who claimed that she was acting in her best interests:

> I told you about my thyroid and how it got very overactive. I was hyper and I was aware of it but the funny thing is, when you're in the middle of it, you don't realise what's causing it until you reach a certain point. And by the time I realised oh right ok that's what's going on and I've got to fix it to my daughter I looked out of control …. So my daughter phoned my doctor behind my back and then landed here one night and dragged me to the doctor the next morning …. She had set up an appointment without me knowing, and I was so angry and I told them both. I said to my daughter you did not have my permission to talk to my doctor and I said to my doctor you did not have my consent to talk to my daughter. So I said you're both handling me and you shouldn't have done that … I got very upset. The doctor said "you clearly need to talk to someone" [a mental health professional] and I said well I've often said that I would like to talk to someone, you know a therapist … but what did they do? They contacted the local crisis centre. The crisis centre came around and took control of my life and I wasn't sure when I would get it [control] back … all that has kind of damaged my relationship with my daughter [crying]. I think the trust is gone, you know from my perspective … I turned to her and I said do you see what happens when you bring in strangers and outsiders that don't understand? I said we lose control of our lives.
>
> (Amy, AKU)

By seeking advice from Amy's doctor rather than speaking with her directly, her daughter's interference inadvertently caused Amy to "lose control" over her life, which resulted in their relationship being permanently damaged. The lack of involvement that Amy had in determining her care and course of treatment meant that she became "very upset" during their consultation, which her doctor took as evidence of Amy's mental instability. Despite requesting to speak with a therapist about this instability, Amy was immediately surveilled by a crisis centre team who restricted her movements and

activities. As a result, Amy became *more* mentally unstable as she began to fear that she would be unable to regain control of her life once her symptoms had passed.

Performing Pain: Blame, Stigma and Stoicism

Pain is understood as "performed" when the person who experiences it reacts to it in ways that are seen to be discordant with the amount of pain that they *should* feel given the type of injury that they have sustained (Thorne 1993; Langellier 2009; Jackson 2005).[70] If a minor injury such as a paper cut were to elicit a loud and tearful response from an adult we would likely think of that person as overreacting. We often only think of injury, and the pain that comes from injury, as "serious" when we see "evidence" of the damage that it has caused, i.e. large quantities of blood. In the absence of this "evidence," we often fail to recognise pain and the extent to which the sufferer feels it (Pryma 2017). In other words, we fail to take an injury seriously as one that requires further medical attention when it does not look "severe." When a person sustains a "serious" injury that results in a large wound and a copious amount of blood loss their pain is often legitimised as an experience that is "genuine" given the nature and extent of their injuries (Sontag 2004). If a person is involved in a car crash and one or more of their limbs are trapped and severely wounded, their cries and shrieks of agony are typically understood to be "normal" reactions to the pain that they are experiencing.

Sufferers who react silently to pain often arouse suspicion and confusion in onlookers who "know" that they are in pain because they can see the severity of their injuries and expect them to react in a certain way (i.e. by shrieking or groaning). The person who witnessed the car crash and saw the egregious injuries that the passenger sustained would undoubtedly be concerned if the victim reacted by remaining silent, perhaps fearing that this was indicative of that person's death. Moreover, by not "showing" their pain when there is "clear evidence" of it, subjects generate unease in onlookers who cannot understand why that person is seemingly "pretending" not to feel pain. This "pretence" might be viewed as a performance that is purposefully enacted in order to give an impression of "stoicism" by a person who feels pain but chooses not to show it. In neoliberal societies such as the US that value stoicism and resistance as positive character markers (Butler 2015; Bracke 2016), the silent and uncomplaining patient is often thought of in a positive way. As noted by M. Cameron Hay in her study of chronic illness and suffering: "[i]n a meritocratic society like the United States, unless one is hospitalised or has been given a terminal diagnosis, there is no culturally acceptable approach to illness that regards endless days of doing nothing as an appropriate response to being sick … people who cannot be productive while chronically ill are at best

[70] By "pain that they *should* feel" I am referring to the pain response that is likely to be expected of that person in response to the injury that they have sustained.

pitied and at worst condemned, their suffering delegitimised and their worth devalued" (Hay 2010, p.268).

The conversation shifts, however, when it centres a person who is not "trained" to position themselves as a victim but who naturally falls into this category. A small child who feels pain and reacts by crying loudly and shrieking hysterically is often believed to demonstrate an *authentic* reaction to that feeling because they are presumed to have not yet learnt *how* to perform pain in order to personally gain from it (Schechter et al. 1993). In this way, when a small child does *not* react by crying loudly or shrieking hysterically to an experience that is known to cause pain it is often viewed as alarming. Because any reaction that they give to that experience is likely viewed as "authentic," a silent response from them would likely be read as suggestive of a deeply felt emotional response to the pain that they have endured. Moreover, because this response is both unexpected and inconceivable in children, it is particularly worrisome for onlookers who often produce an affective response to the child's non-expression of pain by crying or shaking on their behalf.

The release of a video showing Omran Daqneesh, a five-year-old Syrian child who was pulled from the rubble of a building in Aleppo that was bombed during an attack in 2016, provides a good example of this. In the video Omran is shown covered in blood and dust and is carried from the building site into the back of an ambulance where he sits in silence and stares straight ahead, conveying no outward sign of shock or disbelief with regards to the attack that he was just involved in. As cameras are directed towards him he stares blankly ahead, at one point touching the blood on his cheek and slowly wiping it on his seat. This video, and the still images that were captured from it, were widely circulated on international news stations as evidence of the devastation that the Syrian conflict was causing to Syria's most vulnerable citizens. In response to this video, a CNN news reporter who covered the attack began to cry on camera and then stated: "what strikes me is we shed tears but there are no tears here [points towards a still image of Omran]. He doesn't cry once, that little boy is in total shock. He's stunned. Inside his home one moment and then lost in the flurry and the fury of war and chaos" (CNN 2016). The reporter's affective response to Omran's failure to react as a five-year-old typically would in that situation (i.e. by crying and shrieking hysterically) demonstrates her recognition of the severity of the emotional trauma that he has suffered. It is clear that Omran has sustained physical injuries as a result of the attack as shown by the blood on his face, but his "natural" response to cry and shriek has been disrupted by his emotional response to the trauma that he has suffered, which has rendered him silent.

AKU patients who experience chronic pain routinely choose not to disclose their pain to family members and close friends for two reasons. Firstly, they view discussing it to be futile because the person who is listening cannot do anything to alleviate it. Secondly, they believe that talking about it will make their pain experience worse. By drawing attention to their pain through their discussion of it, patients feel that they are likely to focus on it in a way that will

exacerbate their pain experience. Thus, for many patients, distractions offer a useful way to effectively manage pain. As noted by one patient: "when I'm thinking hard about work I'm not conscious of my pain … if I'm not working or if I'm not you know with the family I just put on a funny movie, you know a comedy show or something. I'll watch it you know just because I know that when I watch that I'm not going to feel pain." This claim is supported by Ronald Melzack and Patrick Wall who, in their study of pain, argue that "[i]f a person's attention is focused on a potentially painful experience, pain will tend to be perceived more intensely than normal" (Melzack & Wall 1996, p.22).

It is important to note that both of the reasons that AKU patients give for avoiding any form of pain disclosure are mutually implicative. The futility of discussing a feeling that cannot be felt by others because it is, arguably, incommunicable (Scarry 1985) adds to the frustration that patients already feel about being in pain, which makes their overall experience of it worse. Proponents of the first argument claim that involving someone else in their misery serves no useful purpose, as it does not rid them of pain and will, potentially, also cause the listener harm.[71] Proponents of the second argument claim that their pain is often significantly diminished when they are distracted by something else. Distracting oneself from one's pain is not specific to the AKU experience, but is commonly communicated by patients within a range of chronic disease groups (Lorde 2017; Charon 2006). As noted by Melzack and Wall, "[e]very sufferer of chronic pain has learned to force himself to concentrate on activities that become so absorbing that pain is not felt or is greatly diminished" (Melzack & Wall 1996, p.22). Because distraction is a common practice amongst people who have chronic pain, AKU patients are able to draw from the techniques that other chronic pain sufferers use when seeking to find different ways of mitigating and/ or managing their pain. During his interview, when asked about how he deals with chronic pain, one patient responded by discussing a film character who designed a rifle whilst in prison in order to distract himself from his feelings of pain. This patient's response is worth quoting at length:

> One of the things that I have learnt about pain is that if you focus on your pain and if you talk about it and if you give it a lot of attention it's worse. There's no question about it. If you focus on your pain you're in more pain and if you focus on other things you're in less pain. And one of the keys to living with pain and alkaptonuria is to ignore it as much as you possibly can. I mean you exercise and you take the medications and you do all of those things but if you obsess and you focus on your limitations and focus on your pain you feel worse. *If you focus on what you can do and you remain active and you get going and you live your life you're in less pain*. You know I have a friend that I tell this story to and I'll tell you the story - there's an old movie, an American movie in black and white …. It's based on a true story and he [main character] got into trouble when he was very

[71] Here I am referring to harm in relation to the negative effects that this information could have on the listener's mental health.

young and went to the penitentiary back in the 30s or the 20s when penitentiaries were run very roughly and *he would get into trouble and they would put him in a box. And it was a box where you couldn't stand up or sit down and it was designed to be painful to teach people to obey the rules of the penitentiary*. And when he was in the box he was in pain, he couldn't stand up straight and he couldn't sit down and it was designed to be painful. And while he was in the box he was a very smart guy and he was into rifles and he designed a rifle and he did it all in his mind and he scribbled on a piece of paper and he designed a rifle. And *while he was in the penitentiary he applied for a patent and he pattented the rifle and when he got out, after he completed his time in the penitentiary, he went into business. He built the rifle and he became a very rich manufacturer* of this rifle that he designed. And he designed it within the box. And his theory was if I think about my pain I'm in pain and if I think about designing this rifle and my mind is on other things I'm not going to be in pain … it's a true story and I remember when I was in more and more pain with alkaptonuria I heard this guy's story and I think it's absolutely true. If you concentrate and focus and obsess about your pain you're in so much more pain. If you focus your mind and you focus on activities and other things in life and just go on then it's not as big a deal … I don't want to talk to my friends about being in pain, I don't want to obsess or focus on my pain and I don't want them to be talking to me about it. I don't even want them to raise the subject because when they do I'm thinking about my poor joints and my pain and it's worse.

(David, AKU, my emphasis)

David's understanding of the role that distraction plays in the sufferer's ability to cope with and/ or manage AKU-related chronic pain has three primary components. Firstly, the patient's individual outlook is essential in ensuring and maintaining a good quality of life. If the patient focuses on what they can do rather than what they cannot do by remaining active and living their life normally (i.e. as they would if they were not in pain) they will be in less pain. In making this claim David argues that patients are, to an extent, responsible for their experience of pain if they choose to focus on it. Secondly, David infers that drawing something positive from a negative experience is an effective way to utilise the time that one spends in pain. By creating a design for a rifle that he would later profit from, the film character turned the negative experience of being in pain into a positive experience (i.e. being rich and successful) that he was able to benefit from it. Had he not been in pain this character might not have devoted the necessary time to this project, and he would consequently not have become a "very rich manufacturer." Thirdly, the person in pain should not focus on *why* they are in pain, but should devote all of their energy into making the most of the experiences that they have whilst they are in pain and should work towards overcoming it. For David, the fact

that prison officials caused the character's pain by torturing him into obedience does not detract from the salience of the character's experience for AKU patients who suffer from pain as a result of having this disease. Although the former's pain experience is purposefully inflicted and the latter is not, both are equally relevant in their exploration of what it means to cope with and utilise one's pain experience.

As previously stated, during their interviews I would often ask AKU patients who suffered from chronic pain to describe their current experience of pain, and they would typically respond by noting that whilst they were talking to me they were less aware of it. In this way, the interview provided a distraction that allowed them to temporarily "forget" their pain. In other words, our conversation served to temporarily "alleviate" their pain by providing them with a distraction that caused them to forget it. As noted by one patient: "when I'm thinking hard about work I'm not conscious of my pain … I'm not conscious of terrible pain when I'm sat here talking to you." By stating that they are less aware of their pain when they are distracted by something that is unrelated to it, these patients inadvertently suggested that their pain experience was, at least in part, within their remit of control.[72]

The AKU patient's ability to control when and the extent to which they feel pain by distracting themselves from it gives critics room to blame patients for their pain experience. It allows critics to question the severity of the patient's pain or, indeed, whether or not they actually feel it. As a result, patients are often assumed to be engaging in a "performance" of pain when or if they attempt to communicate their experience of it. Knowing this, patients often decide not to disclose details of their pain and, where possible, to pass as "normal" or unaffected by it. Contrary to their intentions, the efforts that they make to contain their pain experience and present a "front" of indifference often culminates in a performance of "non-pain" that is at odds with their bodily sensations and emotional responses to that experience. By blaming patients for their pain, critics devalue the negative impact that chronic pain has on shaping patient lives in relation to their current abilities and plans for the future (Bury 1982; Charmaz 1997). In addition, they suggest that any sympathy that the patient is given because of their pain experience is unwarranted because it is within the patient's ability to act in order to alleviate it. In other words, because the patient can choose *not* to experience pain, those who are in pain have therefore chosen to remain in pain, therefore they are "undeserving" of sympathy.

On occasion, vitiligo is assumed to be a sign of that person's involvement in military combat. Mistaking their visible symptoms as signs of "injuries" that were sustained during battle, those who make this assumption typically view that person favourably as someone who bravely "fought" for their country. As noted by one participant:

[72] Here I do not wish to argue that it was easy for patients to "switch off" their pain and live normally without it, rather I am arguing that patients were afforded a degree of control over their pain by knowing how to temporarily alleviate it (i.e. through conversing with me).

> I think most people think it's like a burn. Like some people think that I'm like a soldier, like I'm returning from war and like something happened to me … my dad was in the military, he retired after 32 years. My brother fought in every war over the last 28 or something years that happened in our country. So for somebody to say that to me it's like no I'm not that guy, I would love to say I was that guy but I can't even lie and go yeah I am. No those guys are a specific breed of men. I'm not that guy, I know those guys, but no I'm not one of them. I just have vitiligo.
>
> (Michael, vitiligo)

For Michael, any credit that he receives when others assume that his vitiligo is indicative of his involvement in war or military conflict generates feelings of guilt and shame. Having grown up in a military household and having witnessed the physical and emotional toll that war causes, Michael understands any praise that is conferred on him in this way to be misguided. By making this mistake, onlookers shift any blame that they might have given him if they believed that he had bleached his skin on to the war or battle that he presumably fought in. By denying and correcting this assumption Michael demonstrates his refusal to perform the identity that they assigned to him. In this way Michael enacts a "non-performance" of pain, and chooses to be seen in a way that directly correlates with how he sees himself: as a person who "just has" vitiligo.

As stated earlier in this chapter, the emotional pain that comes from the vitiligo participant's lived experiences of having this disease and receiving negative attention often influences the rate of the disease's progression by inducing stress and causing flare-ups. These flare-ups make the condition more visible to onlookers and, thus, increase the amount of attention that the participant receives. Whilst this can, and often does, lead to prolonged periods of seclusion in participants who do not want to be seen by others because they fear being ridiculed, it can also provide participants with a platform to use their visible differences in ways that they deem "productive." This often included engaging in advocacy work that showcased their visible differences in order to generate awareness of their condition and increase funding for it. As I will later discuss in my chapter on personal responsibility, this advocacy work was viewed by many as a way to shield others with the condition from the negative attention that they received by making it more well known and, thus, more understood. In addition, it was viewed as necessary in building the self-esteem of those who have it but who do not regularly see other people with it.

As noted elsewhere in this thesis, people with vitiligo are often mistaken for people who have sustained "injuries" during a fire or some kind of household accident. Typically, this assumption induces feelings of pity in the onlooker and that person's vitiligo is viewed as a

"scar" that will forever serve as a reminder of that experience. In addition, onlookers also commonly mistake vitiligo as a sign that the participant has attempted to bleach their skin and failed to do so.[73] Those who make this mistake commonly blame the person with vitiligo for seemingly engaging in an act of "vanity" and show little compassion towards them. In both cases, vitiligo is understood to signify physical pain, which is directly at odds with the participant's lived experience of it. As previously noted, vitiligo does not *directly* cause feelings of pain but can *lead to* experiences of pain by causing mental health issues that often result in self-neglect. Assuming their skin to signify pain and/ or pain experiences, onlookers often express an interest in touching the skin of people with vitiligo in order to see if it is "rough" or "smooth." As noted by one participant: "some of them [onlookers] they be like well it [skin] still feels the same and I'm just thinking well yeah because it's just skin! My skin color's just changed. With some people I don't know if they think it's going to be rough or whatever but they do, they be like 'it [depigmented skin] feels just the same as your other skin, the brown part' and I'm like yeah it is." Assuming that the variances in skin colour suggest that their skin will feel "different" (i.e. rough), onlookers often "test" this theory by touching the skin of the person who has vitiligo. This often leaves people who have vitiligo feeling alienated and/ or marginalised within a community that makes them feel "Other" because of their condition.

Conclusion

As this chapter has shown, the understanding that pain is incommunicable is largely the result of two mutually implicative factors: firstly, because pain "actively destroys language" (Scarry 1985) it cannot be related through our primary mode of communication. As a result, all knowledge of it as a felt experience is lost through this channel. Secondly, because our understanding of pain is largely informed by social and cultural conceptualisations of what pain is, our experience of pain is likely to vary depending on where we come from (Morris 1991; King 2008). This variance subsequently means that the degree to which we feel pain is often contested by those who do not feel it in the same way. Returning to the example of the paper cut that I used in the introduction, as an adult, if I reacted with loud shrieks and groans to this "minor" injury I would likely be thought of as "overreacting" in order to gain attention and sympathy from others. My "overreaction" would subsequently be read as a "performance" of pain that was purposefully enacted by me in order to generate attention and/ or sympathy. Moreover, because this injury is relatively common, it is likely that my audience would also have had a paper cut at some point in their lives, which, undoubtedly, would then inform their reaction to my reaction. Remembering their own experience of "pain" following a paper cut, they would likely judge my reaction to theirs and conclude that mine was disproportionate to

[73] For people of colour, skin bleaching is often understood to be indicative of that person's feelings of shame and low self-esteem with regards to their racial identity. It is assumed that that person is bleaching in order to "look white" and, therefore, that they dislike "looking black."

the amount of pain that was felt. Failing to account for the different ways in which we might feel pain based on our social and cultural conceptualisation of what pain is, my pain and pain reaction would be viewed objectively rather than as a subjective experience that I alone was feeling.

The *expectation* of pain, and the subsequent expectation of a particular reaction in response to that pain, is intimately tied to the egregiousness of the incident that caused it. When a person is involved in an incident that is known to cause harm (i.e. a car accident) we anticipate that they will experience pain and that they will react accordingly (i.e. by shouting and shrieking). If they fail to produce this response we become concerned and often assume that there is a worse underlying issue that is preventing that person from expressing their pain (as shown in the example of Omran Daqneesh). For AKU patients, because the disease symptoms that cause their pain cannot be seen, they often feel required to perform their experience of pain in order to be viewed in relation to it. Because their pain is chronic, it is usual for patients to become used to their pain to the point where they do not recognise it until it is a new sensation (i.e. until it is felt in a part of their body that it previously was not felt in). This experience directly correlates with Leder's theory of "dys-appearance," whereby "[t]he body emerges at times when it is away from an ordinary or desirable state, as in times of pain and disease" (Leder 1990, p.90). By "performing" their pain in order to appease audiences who are doubtful of it, AKU patients articulate their pain in a way that largely misrepresents their experience of it.

When discussing their pain in dealing with their condition, vitiligo participants often commented on the ways in which their emotional responses to negative stares and comments informed their physical reactions to these incidents. Undergoing prolonged periods of stress, many argued, exacerbated their disease symptoms, which, in turn, made their disease more visible to others and consequently drew greater attention from them. I will now turn to my chapter about personal responsibility and the ways in which this concept disadvantages some whilst privileging others in order to shed further light on the ways in which physical, social, financial and environmental stressors that are largely outside of the individual's control negatively impact those participants who are most vulnerable, and how that contributes to their feelings of social isolation and invisibility.

Being a Good Patient: Inequality, (In)Visibility and Personal Responsibility

> If no one smoked cigarettes or consumed alcohol and everyone exercised regularly, maintained optimal weight on a low fat, low refined-carbohydrate, high fiber-content diet, reduced stress by simplifying their lives, obtained adequate rest and recreation, understood the needs of infants and children for the proper nutrition and nurturing of their intellectual and affective development, had available to them, and would use, genetic counselling and selective abortion, drank fluoridated water, followed the doctor's orders for medications and self-care once disease was detected, used available health services at the appropriate time for screening examination and health education-preventive medicine programs, the savings to the country would be mammoth in terms of billions of dollars, a vast reduction in human misery, and an attendant marked improvement in the quality of life. Our country would be strengthened immeasurably, and we could divert our energies – human and financial – to other pressing issues of national and international concern … The choice is individual responsibility or social failure.
>
> (Knowles 1977, pp.75–80)

> [P]ersonal responsibility should be right at the heart of what we are seeking to achieve. But people's ability to take personal responsibility is shaped by their circumstances. People cannot take responsibility if they cannot control what happens to them.
>
> (Marmot 2016, p.51)

Biological citizenship is a term that is commonly used to describe the state's role in promoting, ensuring and sustaining the health of its citizens. It delineates the extent to which the state should be held responsible for the health of individual citizens, and the degree to which personal responsibility should coincide with the state's involvement in individual health care needs (Petryna 2004; Banda 2015). In other words, it considers whether or not the state has a duty to actively intervene in processes that inform and/or prohibit "good health." Conversations that consider the role of the state in individual processes of "good health" often centre the question of responsibility: is the state

responsible for providing health care to those who do not actively seek to maintain good health behaviours themselves?[74] Should the individual take sole responsibility for their health? Should the state work with the individual in their efforts to assume personal responsibility and, if so, how could this be practically implemented?

Central to these questions is the notion of "deservability," whereby individuals are often deemed "worthy" or "unworthy" of state or federal assistance based on the extent to which they can be considered "deserving" or "undeserving" of their poor health outcomes. If a person is diagnosed with a debilitating genetic condition they are not typically considered "blameworthy" for their illness because it is understood to be the result of circumstances that are beyond their control (Mounk 2017b). However, if a person becomes "ill" because they have contracted a sexually transmitted disease they risk being judged to be "at fault" for their predicament because they could be assumed to have acted "recklessly" or "carelessly" by having unprotected sex (Mounk 2017b; James 1993; Berger 2004).[75] Whilst both conditions result in poor health outcomes, the former's lack of responsibility means that they are often socially and politically deemed to be "deserving" of public assistance, whilst the latter are often understood to have brought about the circumstances themselves, making them "undeserving" of that assistance. As a result, the "undeserving" are stigmatised and invisibilised within a narrative that suggests that they are largely "in control" of their health because they are able to assume personal responsibility for it (Marmot 2016; Mounk 2017b).

In neoliberal economies like the US, the privatisation of essential health care facilities such as hospitals, pharmacies and dental practices means that health care is available to some and not to others (Hill 2016; Chernomas & Hudson 2013). As I have argued elsewhere in this thesis, employers often offer private health insurance as a "benefit" for employees in addition to their salary.[76] This benefit allows the employee to visit their primary care physician when they need to, and typically covers the costs of surgical procedures that patients might require as they age. Recently, national debates concerning the US health care system have focused on the role that pre-existing conditions plays or should play in determining who is eligible for medical insurance (Illing 2017; Gawande 2017). Many medical insurers view patients with pre-existing conditions as "high risk" because they are more likely to require regular medical care and/ or costly procedures in the future, which means that they are less likely and/ or willing to insure them (Jacobs & Sommers 2015). Taking active responsibility for one's health involves regularly seeing a doctor for health check-ups and following medical advice if it is given. Therefore, those who are uninsured or underinsured because of

[74] For example by eating a balanced diet, exercising regularly, not smoking etc.
[75] Note that not all sexually transmitted diseases are contracted because of a failure to use effective protection. HIV, for example, can be contracted from mother to child if the mother decides to breast feed her children.
[76] Note that the employee's income might be reduced in order to subsidise the cost of their health benefits.

their pre-existing conditions are unable to meet that goal and, therefore, cannot take full responsibility for their health.[77]

In his book *The Age of Responsibility: Luck, Choice and the Welfare State* Yascha Mounk discusses what he labels the "Responsibility Framework," which outlines how social and political attitudes in the US often equate being "responsible" with being "deserving" (Figure 1.). In accordance with this model, citizens who have acted "responsibly" by eating a balanced diet, exercising regularly, not smoking etc. are understood to have taken active steps to ensure that they remain "healthy," which means that they should not be blamed for any poor health outcomes that later occur. Moreover, because they are not "at fault" for their poor health outcomes they are "deserving" of public assistance. As Mounk argues: "whether somebody should receive public assistance boils down to an inquisition into the history of their actions: whether they are in need because of their own choices for reasons beyond their control, such as a genetic disease or a car accident. If the former, we don't owe them anything. If the latter, we might give them a hand" (Mounk 2017a).

Whilst Mounk is correct in claiming that genetic diseases and the debilitating symptoms that might occur as a result are widely understood to be beyond the individual's control, chronic disease patients often continue to be blamed for having poor or worse health if they fail to effectively manage their everyday disease symptoms. Patients who do not heed their doctor's advice (for example by failing to take their medication or by carrying out an activity that they are not suited for) are often thought to be "irresponsible" by those who believe that one should automatically heed one's doctor's advice, which often leads to individual blame. As noted by Margaret Reid and Alexander Clark in their study of living with chronic heart failure, "[t]he moral status of patients is judged by their ability to conform to professional prescriptions; thus 'good' patients are those who comply, and non-compliers are viewed as failures" (Reid & Clark 2002, p.142).

[77] By the term "underinsured" I am referring to the state wherein a person does not have the medical insurance that is required in order to meet the full costs of their health care expenditure.

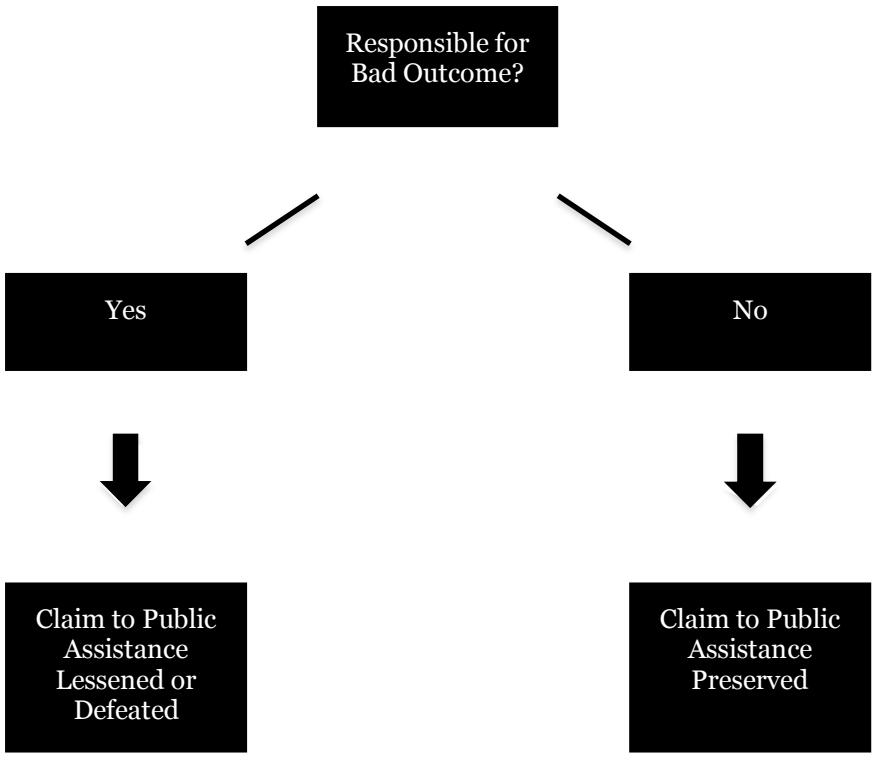

Figure 5. "The Responsibility Framework" (Mounk 2017, 20)

Proponents of the "Responsibility Framework" simplify connections between what they understand to be the "choices" that people make and the outcomes of those choices. According to this logic, if an alcoholic drinks consistently throughout the day and, as a result, later develops liver poisoning, they are directly responsible for their poor health outcomes. Similarly, a diabetic who routinely consumes sugary drinks and snacks is seen to be responsible for any negative health outcomes that may occur (i.e. hyperglycaemia),[78] and a person who is severely overweight because they eat excessively is thought to be responsible if they later develop type 2 diabetes or heart disease (Aday 2001; Mounk 2017b). In each case, the "poor choices" that the individual has made means that they are directly "at fault" for their poor health outcomes, which, in turn, means that they are undeserving of public assistance.

Attitudes that suggest a direct correlation between "choice" and outcome omit three key considerations. Firstly, individual behaviour is, at least in part, socially and environmentally determined. The diabetic who routinely consumes sugary drinks and snacks because they live in a "food desert"[79] that makes it largely impossible for them to access nutritious food is not solely responsible for having poor health as a result of their poor diet. This person cannot be held fully accountable for the "choices" that he or

[78] Hyperglycaemia is the medical term that is used to describe high blood sugar (glucose) levels. This is commonly experienced by people with diabetes.
[79] A "food desert" is a term that is used to describe a neighbourhood or residential area with minimal access to healthy or nutritious foods. These areas tend to disproportionately house low-income people of colour.

she has made because those choices are, at least in part, informed by the social environments that have produced them (Walker et al. 2010; Winne 2009). Secondly, differences in wealth and income largely determine the choices that people *can* make with regards to their diet and exercise regimes. In the US, high calorie foods with low-nutritional value (i.e. fast food) are often significantly cheaper and more readily available than "healthy" foods that provide high nutritional value (Smith Maguire 2018). This is particularly the case in low-income neighbourhoods that have high populations of racial and ethnic minorities (Bay & Fabian 2015; Reese 2019). If citizens cannot afford to pay for "healthy" foods that would allow them to improve their overall health, and are faced with the decision to either consume cheap food with low nutritional value or not eat at all, they cannot be held fully responsible for the poor health outcomes that they suffer as a result. Thirdly, it is possible for people who make "irresponsible" decisions that cause poor health outcomes to do so because they have underlying health conditions that spur their "irresponsible" behaviour. Mental health issues such as depression, anxiety, body dysmorphia etc. can directly lead to poor physical health outcomes that necessitate additional medical care (Frisco et al. 2013; Heiskanen et al. 2013). If a person who is depressed seeks comfort in food and, as a result, eats excessively and becomes obese, can they be deemed "responsible" for the negative health outcomes that might occur as a result of their obesity?

By emphasising the importance of personal responsibility in the everyday lives of chronic disease patients, proponents of this idea argue that patients should and can take an active stance towards maintaining their health by making "good choices." In this way they grant the patient autonomy by suggesting that they can largely determine the degree to which their chronic disease negatively influences their life (Lupton 2012; Galvin 2002). However, as I have already argued, this claim also makes clear the ways in which numerous patient's are *assumed* to be able to make "good choices" when, in fact, they cannot. For AKU and vitiligo participants this assumption operates both within disease groups and outside of them. During their interviews numerous participants from both disease groups described how they were routinely criticised by other group members for seemingly "choosing" not to subscribe to healthy behaviours such as routinely visiting their primary care physician and/ or eating "healthy" foods. This within-group criticism was disproportionately aimed towards those who, because of financial and/ or social constraints that stem from long-standing social biases and/ or systemic inequalities, were unable carry out medical advice. As a result, those who could not assume personal responsibility were often left feeling marginalised within their disease groups and reported feeling "unseen" in relation to their incapacity to assume responsibility.

This chapter will be divided into two sub-headings: Stress, Resilience and Well-Being and Personal Responsibility and Mental Health. The first will outline the experiences of

two patients, Anthony (vitiligo) and Janet (AKU), in order to demonstrate how low-income participants are particularly vulnerable to chronic stress, which, in turn, often significantly exacerbates their disease symptoms and worsens their overall disease experience. Within discourses surrounding personal responsibility and the need for resilience the limitations that these patients face in successfully engaging with disease management strategies are often overlooked. Moreover, because their limitations are not taken into consideration, these participants are often judged in relation to other people with their condition who, because of their social and financial success, are able to effectively manage their condition. In this way, low-income and/ or marginalised participants are invisibilised within a narrative that does not make allowances for their personal circumstances.

The second sub-heading will outline how personal responsibility is closely tied to notions of control. For participants who are unable to positively control their diet, work load and/ or lifestyle because they are socially and/ or financially limited their ability to assume control over their disease symptoms by effectively managing them is significantly reduced. In addition, participants who are neglected in medical settings are often unable to control the degree to which their symptoms are marginalised during these visits. This neglect may be the result of institutional and/ or systemic biases that are directly tied to race, gender, class, sexuality etc. (Washington 2008). By considering the extent to which contemporary discourses concerning hope, resilience and personal responsibility affect the everyday lives of AKU and vitiligo participants, this chapter will outline the different modes of seeing that inform the patient's feelings of (in)visibility within social and familial settings. Building on Mounk's "Responsibility Framework," I will argue that contemporary assumptions about the individual's capacity to take responsibility for their health overlook the financial, social and political restrictions that render many incapable of doing so. In this way, the individual is invisibilised within a system that stresses a need for personal responsibility whilst overlooking the individual's (in)capacity to assume it. Moreover, I will show how, by failing to "see" participants in relation to their incapacity to assume personal responsibility, critics overlook the numerous ways in which systemic and institutional inequities continue to affect some participants and not others.

Stress, Resilience and Well-Being

Over the past two decades researchers have become increasingly interested in the links between psychological stress and physical health (Geronimus et al. 2006; James 1994; Warren-Findlow 2006). Studies suggests that chronic stress leads to an increase in allostatic load (defined as a gradual "wear and tear on the body") (Ogden 2012, p.259), which significantly increases the risk of developing diseases such as cancer, fibromyalgia, lupus,

diabetes and heart disease (Parente et al. 2013; Beckie 2012; Randy 2007). People who do not have the financial means to mitigate everyday stressors by offloading to a counsellor or to their peers, or who cannot take the leisure time required to participate in activities that are known to decrease stress (such as yoga, hiking or meditation), are particularly at risk.[80] Stress typically occurs when social, environmental, financial or familial demands exceed an individual's ability to cope with them (Glaser & Kiecolt-Glaser 2005). By increasing our adrenalin and provoking our "fight or flight" mode when we perceive danger, temporary periods of stress can be beneficial and, potentially, life saving.[81] However, when stress becomes chronic it is both useless and harmful to our bodies (Griffith et al. 2013; James 1994). As noted by Shannon Sullivan in her study of the physiological responses that our bodies produce when we are confronted with stress in the form of sexist and/ or racist oppression:"[w]hen the body undergoes a physical or social challenge it temporarily produces extra hormones, such as adrenaline, that helps the organism meet the challenge, and then ceases producing them when the challenge has passed … In the case of ongoing stress, however, the body doesn't stop its extra hormone production, resulting in high allostatic load … weathering the body's systems of regulation, which produces health problems such as cardiovascular disease, diabetes, and accelerated physiological (versus chronological) ageing" (Sullivan 2015, p.106).

For most people, temporary periods of stress are a normal part of everyday life. Stress comes from a multitude of sources, many of which are unpredictable and unavoidable (i.e. dealing with unexpected loss). Chronic stress, however, is more likely to occur in those who have little control over their lives in terms of income, social mobility, or environmental circumstances (Mounk 2017b). In his book *The Health Gap: The Challenge of an Unequal World* Michael Marmot argues that the degree to which an individual is able to control his or her life directly shapes their health outcomes. Because "[p]overty and inequality are deeply disempowering," he argues, those who have minimal control over their lives "do not feel able to make healthy choices" (Marmot 2016, p.62) which negatively affects their health outcomes. According to Marmot, if a person can afford to buy nutritious food, has the leisure time to exercise regularly, can take regular breaks and/ or vacations from work etc. they are more likely to have positive health outcomes as a result. They are less likely to suffer from chronic stress, and are, therefore, less likely to suffer from the negative health consequences that occur as a result. The degree to which they are able to control their lives directly informs the personal choices that they are able to make, which, in turn, directly speaks to their ability to take responsibility for their actions.

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[80] For further information about the health benefits of these activities see: Kiecolt-Glaser, Janet et al. (2010), 'Stress, Inflammation, and Yoga Practice' *Psychosomatic Medicine*, 72(2), pp. 113-121; Grossman, Paul et al. (2004), 'Mindfulness-Based Stress Reduction and Health Benefits: A Meta-Analysis,' *Journal of Psychosomatic Medicine*, 57(1), pp. 35-43; Ross, Alyson and Thomas, Sue (2010) 'The Health Benefits of Yoga and Exercise: A Review of Comparison Studies,' *The Journal of Alternative and Complementary Medicine*, 16(1), pp. 3-12.

[81] An example of this would be when we step into a road and see an oncoming car approach us at a high speed. Because we fear being hit by the car our stress levels increase, and our response is typically to move out of the road as quickly as possible in order to avoid being hit.

In order to discuss the importance of choice in questions of self-responsibility and self-care for AKU and vitiligo participants I will turn to two case studies: Anthony (vitiligo) and Janet (AKU). Both participants are from low social and economic backgrounds and self-identify as African-American and Native American respectively. Whilst I was able to speak with a number of African-American vitiligo patients, Janet is the only non-white AKU patient that I was able to speak to. Because of their precarious finances and limited social mobility, both participants expressed uncertainty about the future in relation to housing and public/ state assistance. They discussed how their inability to afford costly treatments prevented them from managing their disease symptoms effectively, and how, as a result, their symptoms worsened. In addition, both related feeling that they were more likely to contract sexually transmitted diseases such as HIV/ AIDS and hepatitis because of the social environments that they were living in. After outlining their individual experiences I will discuss the ways in which their relative disadvantages influenced their overall disease experience in relation to disease visibility and social marginalisation. This will include a discussion of the structural/ systemic disadvantages that they faced as racial minorities both within hospital settings and outside of them. I will then point to their experiences of feeling "invisible" within discourses that centre patient success stories as demonstrative of the achievements that *all* patients can make if they "work hard" enough. In doing so I will highlight the problematic use of these examples in discourses that suggest a causal link between personal responsibility, choice and outcomes.

Anthony

Anthony was diagnosed with vitiligo at the age of 19. At the time of our initial interview he had been living with the disease for 25 years, and had experienced periods of symptom progression and regression at varying rates. Anthony was consistently abused by his mother, father and brother throughout his childhood, which led him to seek kinship ties with other people in his local community. He joined a gang at a young age and was initially tasked with "petty crimes" before later selling drugs on a casual basis. [82] Shortly after his 17th birthday Anthony was convicted of a crime that he chose not to discuss during the interview, and was sentenced as an adult to 3 years in a state prison. Whilst he was in prison, Anthony decided to "get [his] education" and focus "on doing all of the right things." For him, this meant abandoning his gang lifestyle and serving his prison sentence without drawing attention to himself by causing disturbances (i.e. by fighting). However, shortly after he arrived in prison another inmate approached him and threated him with sexual assault. This inmate continued to threaten him on a regular basis and, because he was "half the size" of him, Anthony felt ill-equipped to protect himself. Fearing rape, Anthony once again "embraced [his] gang lifestyle" and fought back despite his small stature. During this fight several other gang members in the

[82] By "petty crimes" I am referring to minor crimes such as theft or trespassing.

prison came to his aid and "sent the guy packing" by verbally and physically assaulting him. Impressed by his fighting skills and gang credentials, these gang members "embraced" Anthony and offered him protection for the duration of his prison stay. The gang "leader" took Anthony "under his wing" and advised him to "get bigger [gain muscle]" so that he could protect himself if he was ever found alone. Shortly afterwards, Anthony dedicated himself to body-building and, within the space of 8 months, gained 50lb of "straight muscle."

After he was released from prison, Anthony returned home and resumed his former life as an active gang member and drug dealer. Shortly after his return, Anthony was involved in a physical altercation with a rival gang member who bit him on his arm, causing minor scarring. Within weeks the area surrounding these imprints began to depigment, and Anthony was left with what he assumed to be a permanent marker of this fight. Thinking that it was nothing more than a scar, Anthony did not seek medical advice. After 4 months his skin began to heal and the affected area began to repigment, eventually returning to normal. However, shortly after this area of skin healed Anthony noticed a new area of depigmented skin on his penis. Not knowing what it was or why it had arisen in that part of his body Anthony began to panic. Prior to the fight he had heard rumours that the man who had bitten him was gay. In the late 1980s when this fight took place, discourse surrounding the HIV/ AIDS epidemic vilified young gay men, in particular, as the primary harbourers and disseminators of this disease (Doyal 2009; Berger 2004). Many believed that HIV/ AIDS is primarily contracted through anal sex and intravenous drug use, which meant that gay men and drug addicts, in particular, bore the brunt of public criticism and fear (Cohen 1999). The "threat" that gay men posed to "ordinary" (understood as heterosexual) people because of their "deviant" behaviour (anal sex) sparked large-scale debates about the moral implications of HIV/AIDS and what it meant to be infected (Berger 2004). In light of this discourse, Anthony immediately assumed that this man's rumoured homosexuality, and the physical contact that took place between them during their altercation, likely meant that he had also contracted HIV/AIDS. In addition, he mistook the depigmented area of skin on his penis as a sign that he was HIV positive:

> The guy that bit me I heard like he was a homosexual, there were rumours about him being a homosexual, so I was worried about AIDS and I went through with getting the AIDS testing. When I got through and I got the AIDS testing and it came back negative that's when it [vitiligo] just completely disappeared, because I was stress free.

Fearing the results, Anthony only took the HIV/AIDS test several months after he first noticed the depigmented area of skin on his penis. In the period between the emergence of these symptoms and the HIV/AIDS test Anthony experienced an onset of chronic stress, which caused further depigmented areas of skin on different areas of this body. After his HIV/AIDS test results came back negative his stress levels

decreased and his skin began to repigment. However, the emotionally and physically taxing lifestyle that Anthony had as a gang member and drug dealer meant that he often experienced periods of chronic stress, which brought about further depigmentation. Anthony eventually sought reassurance from his primary care doctor, who subsequently diagnosed him with vitiligo. Although he was momentarily perturbed by this diagnosis, Anthony was reassured by the doctor's explanation that it was "what Michael Jackson had" and that it would not negatively affect his physical health. However, a few weeks after this diagnosis Anthony's vitiligo spread to highly visible parts of his body including his face and hands, which spurred feelings of embarrassment and shame. During the interview Anthony once again attributed this particular flare up to the hectic and volatile lifestyle that he had at the time, and the toll that it took on both his mental and physical health:

> It [vitiligo] came on again later on because I had a like very stressful lifestyle. I had a lot of stress going on being in a gang and being homeless in a gang and living on the streets. You know because like selling drugs is not something that's like you know very lucrative, so you know selling drugs and doing all these different things and what not and living day to day and all that stuff was very stressful in itself. So my stress was compounded on all of these different factors and my vitiligo got worse. So I definitely think stress is very important, it's one of the particular reasons why vitiligo may flare-up.

The culmination of all of the social and financial stressors that Anthony was dealing with (being in a gang, being homeless, and having a meagre and irregular income) took a physical toll on Anthony's body that was made visible through the exacerbation of his disease symptoms. Because vitiligo is an autoimmune disease and the immune system is particularly responsive to feelings of stress and anxiety (Glaser & Kiecolt-Glaser 2005), it is unsurprising that Anthony's flare-ups occurred during this period. The damage that his precarious lifestyle was causing to his body (through lack of shelter, a poor diet and limited access to medical care/ treatment) resulted in a renewed onset of chronic stress, which subsequently made his disease immediately visible to onlookers.

Anthony spent the next two decades in and out of prison, experiencing varying degrees of depigmentation and repigmentation depending on his stress levels. He began to "accept" and "embrace" the changes that his condition had made to his appearance when he was "roughly 95%" depigmented. Because his appearance was no longer "splotchy" (a word that Anthony used to describe how his skin looked when he had both white and brown areas of skin), he did not typically attract negative attention from onlookers and, as a result, was more comfortable when interacting with others in informal social settings. Moreover, because most of his original (dark) skin colour had depigmented, he was able to pass as a "light-skinned" black person to those who, by

looking at him, did not know that he had vitiligo. This afforded him a degree of invisibility by allowing him to be seen in a way that was separate from his condition. For Anthony, this was important because it enabled him to regain the self-confidence that he lost when his skin was "splotchy" and he was immediately seen in relation to his condition.

During a subsequent stint in prison Anthony developed lupus (an unrelated autoimmune disease), and he was required to take drugs that inadvertently re-stimulated his pigmentation. Seeing his skin "change back" and become "splotchy" again was devastating for Anthony, who had by this point adjusted to the way that he looked when he was mostly depigmented. As a consequence, he experienced a prolonged period of depression that was amplified by a number of social and familial problems that he was also experiencing:

> My lupus was really bad so I started taking all these steroids and what not to help me get back to functioning right and the medication brought back half my colour. I instantly went into a very long depression, and it was compounded by a whole load of different other problems: loss of family members, loss of loved ones, being incarcerated. And I had just had 2 sons back to back and I'd never had any responsibility before. Not being able to be in their life and things like that you know it compounded the mental stress and everything. Just all these different thoughts of how they would see me and things like that when they do see me it was very stressful, you know? And I didn't want to accept that my skin was [repigmenting], I was mad. I was like man I've finally got a chance to look in a mirror and be ok with this person I saw that I did not grow up with. I never even knew this person but now I know who this person is because I accept him because he's me and now it's changed again.

Shortly after he was diagnosed with lupus Anthony was released from prison. In an effort to gain meaningful employment in order to support his family, he immediately applied to a series of low-skill, low-wage jobs, most of which were in the fast-food industry. Having previously experienced discrimination because of his vitiligo from former employers he knew that this job search would be difficult, particularly now that he once again had "splotchy" skin that would likely cause employers to discriminate against him. After being rejected from numerous fast-food restaurants and factories Anthony returned to "the streets" where he knew he would be able to continue selling drugs. After learning that his vitiligo was highly visible during his stints in prison, I immediately assumed that Anthony's experiences must have been difficult whilst he was in there because I assumed that it would, potentially, make him a target. When I asked Anthony whether this was the case he laughed and said that the opposite was true – vitiligo marked him as different in a *positive* way because it made other inmates

fear him. Because most of the inmates had not heard of vitiligo they immediately assumed that Anthony had been involved in a fire or a gang-related attack, and, as a result, concluded that he was a formidable figure who should be avoided and/ or treated with respect:

> I had a different persona in prison, like you know my nickname was pit because the colouration on my face was kind of like how it is now. My nose was white and stuff so they [other inmates] used to call me red nosed pit. So I embraced that as far as like ok yeah that's me, that's pit you know. They call me pit bull so I'm a pit bull, I've got the designs and markings. And then when it started spreading and it started spreading even more everybody started calling me pale face pit. So you know the persona of being that tough guy as a pit and having this unique look you know it kind of, how would you say, it kind of blew up my persona and things like that. So when people [other inmates] would see me they'd say "oh that's pit, there goes pale face" you know and different things like that. And I associated that name and they associated that name with you know a name of strength, so I turned it kind of like into something I gather strength from. Because people embraced me as being this person and this figure and things like that in my world.

Much like gang tattoos or clothing signifiers, Anthony proudly "wore" his vitiligo as a sign of his physical strength. In doing so his vitiligo functioned as a form of protection, warding off any violent threats that other inmates might have otherwise posed. After he began conceptualising his vitiligo in this way Anthony began to think of it positively as something that he could "gather strength from" rather than as something that negatively marked him as "different." He carried these feelings throughout his life and, when he was in his mid-thirties, his life began to stabilise. He gained custody of one of his two children, got a job as a counsellor for people who had formerly been incarcerated and were struggling to adapt to life outside of prison, began a PhD programme at his local college, and started volunteering in his local community as a vitiligo advocate. During this time he witnessed his vitiligo regressing and progressing at different stages in accordance with ordinary everyday stressors (i.e. being a parent, working etc.). At the time of the interview his vitiligo had largely stabilised and was highly visible on his face, hands and neck.

Janet

Janet and I were first introduced through the AKU society, a leading AKU charity that is currently based in Cambridge, UK. After hearing details of my research through a blog post,

Janet contacted several AKU society staff members who then gave her my email address. Because, at that time, Janet lived in California and I was conducting my fieldwork in Washington DC, we agreed to do our initial interview over Skype. Whilst doing preliminary research in online patient forums I saw that Janet had been particularly active on two patient advocacy websites, often posting on both several times a day. These posts would detail how her day had been, what tasks she had managed to complete, and what tasks she had not yet managed to complete because of her disease-related fatigue. At the time of the interview Janet had two chronic health conditions: Multiple Sclerosis (MS) and AKU. During the interview she outlined the different ways in which both diseases coincide with each other, and how this negatively affected her overall health. She also discussed how she often gets confused about which symptoms are the result of which disease. Because her MS routinely caused incontinence, Janet wore sanitary pads in her underwear every day. Her incontinence, coupled with the dark urine that she had because of her AKU, meant that these pads showed daily evidence of both conditions and the combined impact that they have had on her body. In addition, the chronic pain that she experienced because of her AKU was made worse by the stumbles and "clumsiness" she experienced as a result of having MS.[83]

At the time of the interview Janet was unemployed and had been seeking disability benefits for three years. She lived in a rural part of California and did not have access to a car, which meant that she was often unable to travel beyond the perimeters of her small town.[84] She lived with her husband in a small house on the periphery of town, and spent most of her time either alone or with her dog. At different points in the interview she inferred that her husband was emotionally abusive, and that this abuse was often triggered by her inability to work or complete household tasks because she was physically limited by both conditions. Her husband worked on a part-time basis in a low-skilled, low-paying job on the outskirts of town, and regularly became involved in arguments and physical fights with other local men. At some point in their marriage he contracted Hepatitis B, which put Janet at high risk of infection. This, coupled with his complaints about being unable to sleep next to her because she would toss and turn in the night due to her chronic pain, meant that, although they lived together, their lives were largely separate. Unlike numerous AKU patients with sympathetic partners, Janet did not feel able to confide her struggles in living with AKU and MS to him and, instead, regularly turned to online patient communities for support.

Janet did not experience any AKU-related symptoms until she was 34 and fell off a ladder at work, injuring her shoulder, hip and the entire right side of her body. The recovery process was long and arduous, and she was eventually forced to leave her job because she could no longer carry out the tasks that were required of her. Prior to this injury, when she was 21 Janet was involved in a car accident that caused significant injury to her neck, which she

[83] Note that stumbling and "clumsiness" are common symptoms of MS.
[84] Cars and other modes of transport are often viewed as essential in rural communities in large states like California because they offer the only means to travel around.

never fully recovered from. At the time of the interview her neck was curved and it caused her a significant amount of pain. Throughout her 30s Janet's pain became progressively worse, and she was unable to find suitable employment. She inferred that this was due to both her physical limitations and discrimination from employers who did not believe that she was capable of doing the job. After numerous failed attempts to find a job Janet applied to her state for disability benefits. At this point Janet had been officially diagnosed with AKU but had not been diagnosed with MS and, because AKU is a rare disease that few doctors and medical insurers have heard of, her application was unsuccessful. Those people responsible for processing her claim did not think that it was a condition that warranted disability benefits, and assumed that she was exaggerating her symptoms in order to receive payments. Janet immediately appealed this decision, claiming that AKU was causing her severe chronic pain that would eventually decrease her mobility and render her permanently disabled. At the time of the interview she had been waiting nearly 3 years to hear the outcome of her appeal, during which time she had little money and precarious health insurance:

> You know I've been waiting for my disability [benefits]. I get no money at the moment from the state or whatever or whoever would give me money, social security disability cheques. And I've been waiting, April 1st it will be 3 years since my appeal after I already had to wait a year from when I first put it in. So I could have died by now but I didn't, I have people who love me thank God.

For almost 3 years Janet was forced to rely on the financial support of friends and family members whilst her appeal was being processed. During this time she had varied and fleeting employment. She house sat for a neighbour who sometimes took trips away to visit her family, and designed a website for a friend who had recently started her own business. Both jobs paid very little and her work assignments were largely unpredictable. In addition, because neither job provided her with health insurance she subsequently became reliant on Medicaid (a federally funded health insurance program that assists low-income families/ individuals with medical expenses. In February 2017 when this interview took place the newly elected President Donald Trump was making significant efforts to rescind the Affordable Care Act (hereafter referred to as the ACA), through which Janet was able to gain access to health insurance. As a result, Janet became increasingly worried that she would lose her insurance because that would also mean that she would be unable to afford her monthly MS injections or visit her doctor in order to get a prescription for her pain relief medication:

> My Tramadol [pain relief medication] is one thing, I get that from the primary care doctor but I won't be able to see him if I don't have insurance. I don't make enough money to go to the doctor to get my prescriptions. I have my house sitting and making the one website but that's not gonna cut it. Anyway, and my prescriptions for the MS are $5,000 a month for injections, which is out of this

> world crazy. I can't believe anybody would pay that, and I did have to go through it like am I really worth $5,000 a month? [Pause] it's hard, that one's hard.

Without health insurance, Janet would be unable to mitigate the effects of either condition by taking medication to alleviate some of her more debilitating symptoms. Because she would be unable to cover the costs of her doctor's appointments it would be impossible for her to access the drugs that she needs, which would substantially affect her overall quality of life. Moreover, her awareness of the precarious situation that she would be in if the policy was to be rescinded caused her to evaluate her worth in monetary terms (i.e. in relation to the money that was being spent on her by her medical insurer). In doing so Janet momentarily stopped viewing herself as a citizen that is entitled to state and/ or federal assistance because of her citizenship rights and began to see herself as a "failed citizen" who, because of her low social and economic status, might not be "deserving" of the money that was being spent on her by medical insurers (Chernomas & Hudson 2013; Mounk 2017b).

Before she was able to get health insurance through the ACA, Janet often visited her "local Chinese doctor" to seek pain relief remedies. For Janet, natropathic medicines such as the ones that were prescribed by this "doctor" offered a viable alternative to orthodox medicines as they were cheap and did not require a prescription. During these visits, after she described her various aches and ailments to her "doctor," she would often be prescribed "special teas" that she would have to prepare in a "special teapot" at the "right temperature" and drink at specific times of the day. During the interview Janet was unclear about whether she believed that these teas worked effectively to relieve her pain, but immediately after she regained health insurance through the ACA she once again chose to pursue orthodox pain-relief drugs such as Tramadol. Janet later began to develop kidney stones (a common AKU symptom), and was hospitalised for treatment. Whilst she was in hospital staff members repeatedly mistreated her by refusing to give her water or tend to her basic needs:

> God they tortured me at that place [hospital]. They didn't give me water, I don't know why they didn't give me water … I didn't even know what a kidney stone was or anything about it at the time but I needed water and I knew that, because I drink water and a lot of it. At the time I didn't drink enough but now I do. But anyway it was a misery there and I will never go to the hospital again with a kidney stone. Now I stay home and deal with it. You don't get morphine at home but you do get to be alone in the dark and [it's] quiet, there's nobody running in the room all the time poking you with needles, you know the stuff that happens in hospitals. And [at] that hospital they were terrible, they never even combed my hair! Anyway I was miserable, so now I know when I have a kidney stone to deal with it at home.

For Janet, this negative experience in hospital was one of many. When she was being tested for MS she was told that she had to have a spinal tap. Fearing the pain that this would cause, Janet contacted a medical specialist that had been monitoring her AKU at random intervals throughout her life. After seeing Janet's MRI scan, the specialist agreed that it was necessary for her to have the procedure. Eventually agreeing to it, Janet underwent the procedure and, to her surprise, was not given any anaesthetic. As a result she suffered even more pain than she anticipated, which meant that the distrust that she felt towards the doctors who carried out the procedure increased. When recounting this experience she noted that she was likely denied anaesthetic during the procedure because she was a "poor person." In doing so she inferred that, because she was poor, her pain did not "matter" to the doctors who were carrying it out:

> I ended up having to take it [have the spinal tap] and I will never do it again and I don't suggest you do either; ask them to put you to sleep. They can put you to sleep and they will. I don't know why they didn't with me, because I'm a poor person and they knew I think. I will never do that awake again. I don't care why I need it, they're not getting it.

The mistreatment that she suffered on this occasion and during previous hospital visits was, Janet believed, directly tied to her poverty. Had she been able to afford private health insurance rather than rely on Medicaid, she argues, she might have been treated more considerately by staff members who would likely have given her pain relief.[85]

As I have stated elsewhere in this thesis, for low-income AKU patients like Janet inequalities persist in the form of access to drugs and therapies that are known to effectively assist patients in managing their condition. The primary drug that is used to manage AKU symptoms is Nitisinone. Administered in tablet form, Nitisinone works by reducing the accumulation of homogentisic acid, which causes ochronosis to occur on the patient's bones, joint cartilage, and skin. Patients who take this drug typically experience less chronic joint pain, are more mobile, and do not have AKU-related skin pigmentation. However, as I have argued elsewhere, Nitisinone is not available to all US patients. Because it is not currently approved by the FDA for use by AKU patients, many medical insurers do not cover the costs of this drug, which means that patients are often required to pay for it themselves. Because this drug costs upwards of $36,000 per year (CADTH 2018) patients like Janet cannot afford it, and therefore must find alternative, less effective ways to help them manage their symptoms. When discussing

[85] Note that some hospitals reject Medicaid and/ or Medicare patients altogether because both programmes are federally funded and do not always fully cover all types of medical procedures. Because they offer limited coverage, recipients of either programme can face discrimination from medical professionals who view them as less "desirable" patients than those who are covered by private medical insurance programmes.

her diagnosis, Janet claimed that her life might have been better if she had not been diagnosed with AKU because she was "too poor" to afford Nitisinone. Knowing that this is the only effective treatment option available to patients, she inferred that being diagnosed was pointless because she was unable to access this medication and was unlikely to be able to access it in the future:

> At one point I was feeling fine and I thought I beat it [AKU] but no I didn't. If I did I would be taking Nitisinone, that's the only way to really beat the symptoms … In my case I think it would have been maybe better not finding out [about AKU] because I can't take the Nitisinone and there's nothing I can do about it [disease symptoms].

As well as Nitisinone, at the time of the interview Janet lacked the financial means to maintain a recommended AKU patient diet, which consisted of minimal amounts of protein and copious amounts of fresh fruit and vegetables.[86] As previously stated, at the time of the interview Janet resided in a rural part of California and did not have her own form of transportation. Her local grocery store was 60 miles away, and there was limited available public transport. As a result, Janet was only able to visit her grocery store once a month and, therefore, had to buy most of her groceries in bulk. The relatively high cost of fresh food when compared with frozen or pre-packaged food meant that the latter was the only viable option for her. Because of her meagre budget, Janet was unable to afford nutritious food that would assist in minimalizing her and improving her disease symptoms.[87] As a result, Janet's principal diet consisted of foods with long expiration dates that could be easily stored in the cupboard or freezer. These foods often had little nutritional value, and prevented Janet from heeding her doctor's advice by undergoing a specific diet to improve her everyday symptoms:

> I need to go on the anti-inflammatory diet, I know that because my doctor told me and I totally agree and if I had more money I would. But otherwise I would eat nothing because it's [fresh food] so expensive… I live in the mountains and it's 60 miles to the grocery store and you can only bring home so much fresh food, fresh fruit and stuff like that and then you're done. And it's not fresh for you know a month and then I only go once a month to go grocery shopping so it's like you're not going to get enough food it you don't eat protein. You know everything that can go in the freezer is good, you know? I would break it up and I have my freezer packed full of food and I have frozen vegetables in there too but it's not the same as fresh leafy yummy vegetables.

[86] This diet was recently outlined by the AKU Society (UK) and made known to patients through their website's advice column.
[87] Here I am referring to the medically recommended diet for AKU patients outlined in the footnote above.

Although she recognised the need to eat specific foods in order to improve her health, because of her circumstances Janet was forced to eat the relatively unhealthy foods that she could afford and locate. If she did not, she argues, she would "eat nothing." Because Janet did not have the option to purchase and consume foods that would allow her to effectively manage her disease symptoms, she had a worse overall disease experience compared to patients who did have the financial means to access these foods. In other words, her relative poverty prevented her from actively managing her symptoms.

Discussion

For participants like Anthony and Janet, their efforts to assume responsibility for their health is thwarted by their inability to do so. Because of their relative poverty, both are prevented from gaining access to effective treatments that will minimise their symptoms and decrease their overall disease visibility. Over the course of their disease both experienced periods wherein their housing circumstances were unstable at best, and both frequently struggled to find employment because of their symptoms. Neither could afford to undertake a recommended diet to help with their symptoms because of its high cost, and both were prevented from taking the most effective medication or from undergoing the most effective treatments because their medical insurance would not cover them and they did not have the independent financial means to pay for these treatments themselves.

In addition to the housing, dietary and medication barriers that both participants faced at different points in their lives, they have also, at different times, experienced physical and emotional abuse from those who are closest to them (Anthony's immediate family and Janet's husband). For Anthony, this abuse caused elevated stress levels that exacerbated his disease symptoms and indirectly led to poor life decisions that negatively affected his overall health and well-being (such as his continued involvement in a gang). During his interview Anthony described how his decision to join a gang at a young age and become involved in criminal activity was the direct result of the abuse and mistreatment that he suffered at home. Had he not suffered that abuse, he argued, he might have avoided this lifestyle and would likely have evaded the subsequent prison sentences that he served. Moreover, had he not been involved in a gang he would likely not have been involved in the physical altercation that caused his first symptoms to appear. During the interview he inferred that, had his life been free from the stressors involved in being homeless, being the victim of abuse, being involved in a gang, having limited employment opportunities etc. he might not have developed vitiligo at all.

For Janet, the emotional abuse that she received from her husband elevated her stress levels and made her more self-conscious of the limitations that both of her conditions imposed on her in relation to the job market and her position as a "stay-at-home wife." His abuse, coupled with the mistreatment that she suffered at the hands of various doctors, made her feel

misunderstood and unseen in relation to the difficulties that she faced in living with both conditions. During the interview she discussed how, because neither are immediately visible and AKU is largely unknown, she often finds it difficult to communicate her symptoms and experiences of living with them to other people because they simply do not understand and, often, do not wish to understand (this is a topic that I discussed in detail in my chapter on pain). Moreover, her awareness of the failure of others to see her in relation to her experiences of living with both conditions prompted social disengagement. At home Janet lived an entirely separate life from her husband, and when she was in public (i.e. at the grocery store) she rarely engaged with other people. At the time of the interview Janet's primary socialisation took place online with other patients who recognised and understood the everyday struggles that she faced.

Studies have shown that the various stressors associated with poverty (i.e. unstable income, housing, healthcare etc.) lead to chronic health conditions such as diabetes, heart disease and stroke (Hill 2016; Takeuchi et al. 2010) and increase the likelihood of contracting infectious diseases (i.e. HIV, hepatitis etc.) (Cox 2011; Holtgrave & Crosby 2003). Studies have also shown that these stressors can exacerbate existing health conditions, which can result in increased rates of mortality (Takeuchi et al. 2010; Domínguez & Arford 2010; Hall 2018). As a result of the numerous structural inequalities and institutional biases that have historically prevented people of colour from gaining full and equal access to the opportunities that have been afforded to whites in the United States, they are more likely to experience limited employment opportunities, unstable and/ or unsuitable housing and poor (or non-existent) health care (Bonilla-Silva 2006; Darity Jr. & Myers 1998; Reich 2017; Perry 2011). Because Anthony and Janet self-identify and are socially identified as African-American and Native American respectively, they are statistically more likely to suffer from the various stressors that are directly associated with poverty.

Around the time of my initial interview with Anthony it was estimated that 1 in 3 black men were likely to go to prison at some point during their lifetime, compared to 1 in 17 white men (DuVernay 2016). Though blacks and Hispanics comprised approximately 32% of the US population, they made up 56% of all incarcerated people ((NAACP) 2018), and black men who committed the same crime as white men received prison sentences that were, on average, almost 20% longer (Ingraham 2017). Critics often argue that these statistics overlook the individual choices that people make in committing a crime or several crimes that result in their incarceration (DuVernay 2016; Alexander 2012). Anthony made a choice to commit the various crimes that resulted in his numerous prison stays, therefore should he not be held responsible for them? And if his crimes can be reduced to the structural and systemic inequalities that he likely faced throughout his life does that absolve him of responsibility for them? I am not suggesting that he should or that he was not responsible for the crimes that he committed. However, I am suggesting that it is important to understand the structural

limitations and systemic inequalities that informed those decisions and made him more likely to go to prison as a result of them.

In a study conducted by the Economic Policy Institute in 2016, researchers found that the rate of poverty amongst Native Americans was "nearly double the national average for all people and 1.7 times higher for children," with 33.8 percent of Native American children living in poverty (Wilson & Mokhiber 2017). It also concluded that Native American median household income is "similar to that of black households, but Native American households experienced much slower income growth than blacks over the last year." According to these statistics, Janet is significantly more likely to experience poverty and is less likely to see high-income growth in her lifetime.
As a result, Janet's circumstances and her inability to assume complete responsibility for her health must be viewed in relation to the systems of inequality that have likely made it more difficult for her to obtain the financial and/ or social capital that she would need in order to do so.

Personal Responsibility and Mental Health

In neoliberal economies like the United States, one's ability to maintain "good health" is largely understood to be indicative of one's "willingness" to take personal responsibility for oneself and one's health behaviours (Mounk 2017b). As noted by Rose Galvin in her work on chronic illness and personal responsibility: "[t]he healthy person is, in effect, symbolic of the ideal neoliberal citizen, autonomous, active and responsible and the person who deviates from this ideal state is, at best, lacking in value and, at worst, morally culpable" (Galvin 2002, p.117). This responsibility does not typically account for the individual's *capacity* to take personal responsibility, but rather focuses on the extent to which the individual is *willing* to do so. Drug addicts are routinely blamed for "lacking the drive" to stop taking drugs, whilst little consideration is paid to the personal circumstances that might have caused that addiction and that might contribute to its continuation (i.e. depression, grief etc.) (Sered & Norton-Hawk 2014). Similarly, when people who have an invisible chronic condition refuse to participate in activities that would involve physical exertion (i.e. swimming), they are often viewed as *unwilling* to participate rather than as *unable* to. This is largely because, to the unsuspecting viewer, that person "looks healthy" and is therefore viewed as "capable" of doing so. When the activity in question would form and/ or maintain "good health" (i.e. swimming, jogging, yoga etc.), the individual runs the risk of being blamed for having poor(er) health because they refused to "look after themselves" by participating in these activities. AKU patients who do not show any visible signs of their condition (i.e. ochronosis) are routinely criticised by those who do not have it and/ or have not heard of it for being "unwilling" to participate in physical activities that directly promote "good health." When internalised, this criticism can lead to self-blame, which can directly cause or contribute to existing feelings of depression. As previously argued in this chapter and in my chapter on chronic pain, the

intimate connections between mental and physical health mean that the former often directly affects the latter. In this way, the negative feelings that might come from criticism could cause a further decline in that person's physical health.

By questioning the subject's *willingness* to take responsibility for their health rather than their *capacity* to do so, critics deflect attention away from any relevant socioeconomic factors that might have contributed to the individual's poor health. Instead, they construct a narrative that suggests that the individual is to blame for their inability to conform to a model of citizenship that centres personal responsibility as its primary tenet (Galvin 2002; Nkansah-amankra et al. n.d.). This model is shaped by neoliberal policies and attitudes that advocate for minimal state involvement in the health and health care of individual citizens (Nkansah-amankra et al. n.d.; Wiest et al. 2015). According to this logic, if a person is ill, their illness should be personally dealt with through health care provisions that the individual is responsible for obtaining. Under the current US health care model (which is based on a privatised multi-payer system) individuals are responsible for ensuring that they have adequate health insurance to cover the costs of doctor's visits and medical treatment for themselves and dependent family members. As I have argued elsewhere, this insurance is typically either provided by employers or by federal programs such as Medicare or Medicaid. However, for the unemployed, underemployed,[88] and for those who do not meet the minimum requirements for Medicare or Medicaid health insurance is often unobtainable. For patients like Janet who are not granted disability benefits because state providers fail to recognise the severity of their condition(s), this could mean that they are left uninsured and chronically unwell.

In order to explore the impact that narratives that centre personal responsibility has on the mental health of those who cannot assume it in greater detail, I will now turn to four individual case studies: Amanda (vitiligo), Amy (AKU), Thomas (vitiligo) and Luke (AKU). All of these participants discussed experiencing feelings of depression as a result of their disease at some point in their lives, with two having experienced chronic depression. In addition, each discussed times in which they felt it necessary to conceal their depression from other people so as not to appear "weak" or "vulnerable" in terms of their ability to manage and/ or mentally deal with their disease. This compulsion, they claimed, stemmed from their awareness of the judgement that they would likely face from others both within their disease group and outside of it if they showed and/ or succumbed to "emotional weakness." Others, they argued, expected them to be "strong" and to demonstrate "strength" in dealing with the everyday challenges that inevitably come with having their disease. As a result of concealing their depression, these participants often felt that their struggles went "unheard" by those who chose not to hear them. For many, our interview(s) offered an opportunity to relate these

[88] By "underemployed" I am referring to those who are unable to work enough hours to qualify for private health insurance through their employer, and to those who work for a company that does not provide medical insurance.

struggles for the first time, and to reflect on the affects that these struggles likely had on other aspects of their health and wellbeing.

Amanda and Amy

I was first introduced to Amanda, an African-American woman with vitiligo, at the World Vitiligo Day conference that I attended whilst conducting my fieldwork in 2017. After hearing about my research she seemed particularly keen to participate in it, and took every opportunity to discuss it with me during the remaining few days of the conference. During breakfast on the final day, Amanda told me that her vitiligo had been the primary cause of her divorce. Her husband, she claimed, made it clear that she was "not the woman he married," and repeatedly related his concerns about her possibly passing the condition on to children that they might have in the future. When he left her, her husband took their car, money and all of their furniture. As a result, Amanda moved in with her sister, where she resided at the time of the interview. During the interview Amanda discussed what she considered to be some of her most challenging experiences in living with vitiligo, which included her mental health struggles following her divorce. She directly related these experiences to the medical neglect that she suffered after she was admitted to hospital because of a severe asthma attack, which she believes triggered her vitiligo:

> What I feel happened is I had a major asthma attack and I'd never had one before so I had to be hospitalised, and whilst I was in the hospital they [doctor] put me on a steroid. And then the doctor went on vacation and when he was gone they [nurses] didn't take me off of the steroid, so when he got back from his vacation I was still in the hospital on this steroid and he was like "why is she still on the steroid?" and they [nurses] were like "well you didn't leave any instructions to take her off." And he was like "but you guys know you don't leave anybody on this steroid for this period of time." And so I had to stay 2 more weeks to be weaned off of this steroid, so I was in the hospital for 4 weeks with this asthma attack. And then I would say when I was out of the hospital like a week later I noticed the first white patch on my hand. And I was like that's strange, that wasn't there before and boom – it just went crazy after that … it was like trauma you know to your body, stress and all that kind of stuff. I mean it wasn't even a week later that I noticed the first white patch on my hand … I saw my primary care physician after that and you know I was like I've got this white patch on my hand [and] I really don't know where it came from. It's not an age spot or you know it hadn't been there before, and the doctor said "well, it looks like vitiligo" and well at that point you know he was like "if it is vitiligo there's no cure," you know this was when I was 28 and I'm 53 now. So this was back a long time ago and I don't think they really knew as much about it. He said there's

> nothing I can do about it so I never actually went to a dermatologist, I just took my doctor's word for what he was saying.
>
> (Amanda, vitiligo)

According to Amanda, her vitiligo was prompted by the medical neglect that she suffered at the hands of an irresponsible doctor and incompetent nurses who failed to discontinue her asthma treatment. She infers that, if her doctor had not left for a vacation whilst she was still undergoing treatment for her asthma attack, or if the nursing staff that replaced him as her primary care givers had known to take her off the steroids that she was on, she might not have vitiligo today. After these medical providers failed in their duty of care towards her, Amanda's primary care physician diagnosed her with vitiligo without offering any suggestions about possible courses of treatment or follow up care. After she was made aware of the fact that vitiligo is chronic and, therefore, incurable, Amanda chose not to visit a dermatologist. Her vitiligo then quickly spread to her stomach, legs, genitals, arms and face. As her vitiligo progressed, Amanda's mental health declined and she began to isolate herself. At the time of the interview she had been diagnosed with severe depression for several years and, as a result, was unemployed. Being unemployed and reclusive exacerbated her depression, which spurred poor health behaviours (such as a poor diet and a lack of regular exercise). This eventually lead to numerous health issues including diabetes and, eventually, a stroke. At the time of the interview Amanda was relying on disability benefits for financial support, as well as her sister and other close relatives fir help with everyday tasks such as getting dressed, bathing and grocery shopping.

According to Mounk's responsibility framework, Amanda's claim to public assistance is warranted because she cannot be held responsible for the bad outcome (unemployment). The medical staff at the hospital neglected Amanda, and in doing so triggered her vitiligo. This led to depression, which, in turn, subsequently caused a number of health issues that left her unable to work. Amanda could not work as a result of these health issues, therefore she was eligible for state/ federal support. However, whilst many would agree that Amanda's inability to work was the result of her physical disabilities (at the time of the interview Amanda's mobility was restricted as a result of her stroke), others would query the extent to which her initial feelings of depression contributed to these poor health outcomes. Did Amanda's depression directly cause her various chronic conditions (i.e. diabetes and vitiligo) and did she have a responsibility to overcome her depression in order to better manage them?

In neoliberal societies such as the US that encourage competition as a means of driving production, depression is a relatively common mental health issue (Hari 2018; Brown & Baker 2013). Conversations that centre feelings of depression and the ways in which people overcome it are well known and regularly shared. These stories typically place the onus on the individual to seek help from their primary care physician and/ or psychologist in order to

begin some form of treatment. Thus, in Amanda's case, critics would argue that she did not do enough to overcome her depression, which eventually caused her numerous health problems and, ultimately, resulted in her financial dependency. These critics pay little attention to the barriers that many like Amanda face in overcoming depression, particularly when that person has a low social/ economic status. In privatised health care systems like in the US, if one cannot afford health insurance that would allow one to visit and seek treatment from a mental health professional one often cannot do so. Similarly, if an individual does not have the emotional support and/ or stability at home that would help them to recover from depression before it led to these conditions, it is unlikely that they would be able to prevent these conditions from occurring. For Amanda, a lack of familial support at home couple with her divorce meant that she was unable to quickly recover from her depression, which ultimately meant that she was more susceptible to subsequent health conditions.

The medical neglect that Amanda suffered, and the subsequent health issues that arose from that neglect, is not uncommon. During their interviews numerous vitiligo and AKU participants discussed encounters that they had had with medical professionals who, through their neglect or mistreatment, directly caused or exacerbated their disease symptoms. Amy's case, as outlined in the previous chapter on pain, offers a clear example of this. The stress that she was under after her doctor recommended that she was surveilled by the crisis team, as well as her concerns about not being able to regain control over her life after her symptoms once again became manageable, meant that her mental health declined further. She directly related this mistreatment to her doctor's failure to understand her needs as an AKU patient, having never heard of the condition and showing no interest in its symptoms. Two years before this intervention took place, Amy had argued with her brother who, failing to understand AKU and its symptoms, accused her of being "lazy" and disinterested in caring for their dying mother. This argument led to what she described as a "six-month period of depression," during which time she received medical care from a different primary care physician and was prescribed treatment. Because her depression was recorded in her medical notes, her doctor at the time of the intervention was able to claim that additional help from the Crisis Team was warranted.

Amanda and Amy's stories differ in that, for Amanda, her depression was the direct result of her clinical mistreatment and, for Amy, her mental illness was assumed because she had a history of depression. However, they are similar in that they both outline how medical negligence and/ or mistreatment can directly cause the onset of symptoms for seemingly "unrelated" conditions. Amanda was admitted to hospital following an asthma attack, and from there she developed vitiligo. Amy was surveilled at home because of her "erratic" behaviour following her overactive thyroid, and as a result suffered from acute anxiety. In both cases both patients felt that their doctors shirked their responsibility as their primary care providers by leaving them in the hands of other health care providers who did not know how to effectively treat them.

Luke and Thomas

At the time of our initial interview Luke was 53 years old and he had received medical care for his AKU at various intervals throughout his life. He was diagnosed with AKU when he was an infant, but the specialist who diagnosed him was largely unaware of the long-term implications of this disease. His family was told that his ears and hands would likely "turn dark" as he got older, but were not informed about the chronic pain that he would likely suffer from or the fact that he would likely be required to undergo numerous joint replacement surgeries over the course of his life. According to Luke: "they [doctor] said that like when you get older your ears are going to turn dark and like the skin between your thumb and forefinger is probably going to kind of turn brown and silly stuff like that. NOBODY said oh by the way it's going to completely destroy your body."

Because of his involvement in numerous clinical trials and studies that the NIH (National Institute of Health) regularly conducted, Luke underwent a series of screening visits to monitor the rate of his disease's progression. These visits were often physically and emotionally taxing, but they offered Luke the opportunity to seek personalized disease-management advice from a leading team of US-based AKU specialists. The visits typically took place over 3-4 days and each time that he attended them Luke chose to go alone.[89] During one visit in his "free time" Luke recorded his emotional response to the tests that he had undergone that morning in his diary, and further reflected on the persistent need that he felt to "remain strong" despite fearing the damage that his disease will likely cause in the future:

> Today.
> Today I don't want to be amazing.
> Today I don't want to be strong. I don't want to try and be super human.
> Today I don't want to over achieve.
> Today I want to be normal, human, frail and embrace my weaknesses.
> These strengths that I rely on…the pushing to always be better, to always do better….that's what I do so I don't break.
> So I don't break down and let all my weaknesses win.
> Some days the strengths are who I really am, other days the strengths are a front…a mask to disguise the ailments and weaknesses that conspire to beat me every day…
> Those days I mask the pain, the weakness, the frailty that is all too real.

[89] Luke often did not have a steady partner when he was required to undergo screening visits and purposefully chose not to take his children with him because he feared upsetting them.

> I mask it from the public, even from myself.
> The strength is very real, and some days I really do feel super human and amazing … but some days I just don't want to be strong … some days it just feels overwhelming and I don't want to fight.
> Those are the days I can really feel the aloneness … even in the midst of a crowd. Sometimes I just don't want to fight … I don't want this disease. I just want to be normal and not have to have to fight so hard to be healthy … I want the luxury to not have to keep such a regimen of exercise and diet and trying to fight every day just to be even minimally mobile and active. And it's very heavy and depressing knowing it's not going to get better … but I don't get to be weak. Quitting does not ever get to be an option. I'm strong because I have to be. I over achieve because there are no other options for me. If I'm amazing, I'm amazing because I have to be. Mediocrity is never an option. Average cannot be accepted or tolerated. I have to push to be super human and smash through barriers and obstacles because the battles I fight are super human. They are not for the weak. The weak will get plowed under and the disease will take advantage of the weakness and exploit it at every turn.
>
> (Luke, AKU [taken from a diary entry, original format])

There are several points that are important to note about this diary entry. Firstly, Luke's awareness of the discontinuity between his outward performance of "strength" and his inward feelings of "defeat" demonstrates his ability to recognise the social performance that he routinely enacts in order to convince others (and himself) that he is coping with the disease. Secondly, his performance of "strength" on days when he feels "weak" leaves him feeling both overwhelmed and isolated "even [when] in the midst of a crowd." This is because others are unable to see past his performance and, thus, have no way of knowing his daily struggles in dealing with his disease. Thirdly, Luke feels the need to be "superhuman" because the "battles [he] fights are super human," which regularly leaves him feeling emotionally drained and exhausted. For Luke, taking a break from this performance would mean letting his "weaknesses win" and surrendering to the "battle" that he continually "fights" with AKU. As a result, the performance must continue. In her discussion of the emotionally and physically debilitating effects of breast cancer Audre Lorde offers a similar sentiment, claiming: "I don't feel like being strong, but do I have a choice?" (Lorde 1997, p.11). For Luke, striving towards maintaining a constant pretence of strength, whilst draining, is necessary in order for him to "not break" and succumb to the temptation of letting his "weaknesses win." These "weaknesses" include both the physical weakness of immobility and the mental weakness of not being able to maintain "good" mental health.

In a similar way, when discussing their struggles with mental health issues during their interviews numerous vitiligo participants argued that the "front" of indifference that they

presented to others who stared at them and/ or made disparaging comments about their appearance was necessary in order for them to ensure their own mental wellbeing. In doing so, many argued, they were able to deflect this attention, which ensured that they did not internalise it and begin to think of their appearance in a negative way. Participants also argued that "remaining positive" about their disease when interacting with others with vitiligo was necessary in order to make sure that they did not negatively affect that person's self-esteem and/ or exacerbate any feelings of depression or anxiety that they might already have because of their condition. One of these participants, Thomas, discussed the responsibility that he felt to regularly post messages of encouragement on social media for those people who looked up to him as a "role model" and relied on his messages of support in order to bolster their own self-esteem. I first contacted Thomas through social media after a number of participants mentioned him during their interviews as a key source of inspiration when they experienced feelings of depression as a result of having their disease. As a leading advocate in the online vitiligo community, Thomas had a platform that allowed him to reach out to a number of people and relate his experiences in living with the condition from a young age.

At the time of the interview Thomas was 23 years old and he had been a regular online presence in the vitiligo community for around 5 years. During periods of mental and/ or emotional instability he would routinely delete or suspend his social media accounts and remove himself from all of the online vitiligo support groups that he was a part of. He viewed this as important in order to ensure that he did not allow his mental health struggles to negatively affect others with vitiligo who expected him to only post messages of encouragement. Typically, he would only remove himself for 2-3 weeks, which would give him enough time to mentally recover from whatever emotional difficulties that he was facing at that moment. However, one time he removed himself for one year, during which time he ignored his phone and did not respond to any private messages that his followers would send him. Fearing that his emotional instability would make him a danger to himself, his followers began to worry. As noted by one during her interview:

> He [Thomas] dropped out of sight for one year. I mean off social media, no one could reach him and no one knew what was going on. Every body was worried, everybody [said] you know have you heard from Thomas? Has anybody reached out? Everybody reached out, I'm talking about he has so many followers all over the country with everybody reaching out and nothing nothing nothing. Out of the blue last week he's on social media and he's telling everyone that he was in an extremely dark place. He was saying, he didn't give all of the details, but that it's possible for someone who's so in love with themselves and has helped millions of people on social media to have a problem that he can't fix. Now he feels horrible about himself when he's given all this information, all of this joy and all of these things to people, now he went inside himself and he couldn't cope.

(Michelle, vitiligo)

Michelle's concern for Thomas after his "disappearance" stemmed from the expectation that she had of him to continue posting messages of encouragement on social media. She, along with millions of followers "all over the country," relied on Thomas for these constant messages of support and became worried when no one could reach him. During his interview Thomas noted that he felt "overwhelmed" by these messages of concern, and that it made him feel "responsible" as a public figure for uplifting others within the online vitiligo community with the "positive energy" that he ordinarily showed but did not have at that time:

> There are people out there who expect some sort of inspirational post or video from me so it just kind of adds that responsibility like hey there are some people out there who feed on your positive energy so [no matter what's] going on in your life always make time or these people because you've grown close to these people and they appreciate you, they appreciate your message … it does kind of add that responsibility, that's it's not just about you anymore. Now you have people that actually look up to you. So sometimes it can get a little overwhelming.
>
> (Thomas, vitiligo)

Because the people who follow him "expect some sort of inspirational post or video" on a regular basis, Thomas felt compelled to continue in his role as an advocate despite the personal struggles that he was facing. Because these people appreciated him Thomas felt close to them, and this closeness made him view his condition in a way that was relational, rather than personal. He no longer viewed his condition and his daily struggles in dealing with it as something that was specific to him, but rather saw his struggles within a broader context of the communal struggles that people with vitiligo typically face.

For both Luke and Thomas, the expectation that others have of them to "put on a brave face" and remain positive despite the physical and emotional toll that their diseases have on them conveys an unrealistic assumption that both *could* lead "ordinary lives" and overcome everyday challenges if they *wanted* to. If both choose not to succumb to the "weaknesses" that follow from their conditions, they will be able to overcome those challenges and maintain the strength that they need to continue in their work as advocates. By placing the onus on them, those who expect Luke and Thomas to remain positive and continue to deliver positive messages to others inadvertently increase the level of responsibility that they feel towards others, and unknowingly add to the burden that they face in dealing with their conditions.

By unintentionally preventing them from showing "weakness," they effectively silence their day-to-day struggles and invisibilise their affective/ emotive responses to dealing with their disease on an everyday basis. This is not to say that Thomas and Luke did not play a role in

this silencing. By removing himself from social media Thomas actively chose not to convey his negative feelings to his online followers, and in doing so limited their understanding of his everyday experiences. Similarly, by masking "the pain, the weakness, [and] the frailty" that he experienced as a result of his disease, Luke chose to omit all of the ways in which he is negatively affected by his AKU, and thus presents a one-sided understanding of his lived experience of his condition. However, in both cases the choices that they made were directly informed by their understanding of how they would likely be received if they were to reveal the negative ways in which they are affected. Luke knew that others would likely pity him if they knew about his daily struggles in coping with chronic pain and fatigue etc., and his efforts to hide these symptoms from others was the direct result of him wanting to avoid this reaction. In a similar way, because he was aware that his daily struggles might negatively affect those who look to him as a source of comfort and support, Thomas purposefully hid those feelings from them by regularly "disappearing" from social media for periods of time. In this way, his failure to disclose information about his daily experiences is the direct result of his anticipation of other peoples' reactions to him if they were to know about his daily struggles.

Conclusion

In his book *Punishment and Inequality in America* Bruce Western argues that "[a]lthough numerous, the poor are invisible in America's affluent society. The everyday hardships of low-income families are unfamiliar to those who are economically comfortable" (Western 2006, p.85). Thus, according to Western, because of their relative comfort, those who are "economically comfortable" fail to *see* the poor because their "everyday hardships" are unknowable to them, despite the fact that they make up a large percentage of the population. Because their experiences and hardships do not in any way relate to the financial stability that the "economically comfortable" know, the latter cannot relate to them and, as a result, fail to "see" them in relation to their struggles. As I have discussed in this chapter and in preceding chapters, "wealthy" participants from both disease groups are significantly more likely than "poor" participants to have access to treatments that will effectively manage and/ or stabilise their symptoms. In this way, "wealthy" participants are significantly less likely than their poorer counterparts to have visible disease symptoms that often result in low self-esteem and body-consciousness. Because of the experiential disconnect between these two groups, the "wealthy" are often unable to recognise the difficulties that the "poor" face in managing their symptoms and routinely hold them to the same standards as the standards that they hold themselves to. This often leaves poorer participants feeling as though they have "failed" in their efforts to assume personal responsibility for managing their symptoms.

Those who, because there are medically uninsured or underinsured, cannot afford to "help themselves" by paying for expensive medications/ therapies are invisibilised in a

system that promotes personal responsibility as a key value that should be upheld by all. Conversely, those who are able to afford good medical insurance (either through their work or personal finances) are able to access effective medications and/ or therapies that help with their disease symptoms, and are understood as acting "responsibly" by taking an active role in their disease management practices. During their interviews numerous low-income participants discussed moments of dismay when they were unable to remain hopeful or positive about their condition because of their inability to effectively manage their symptoms. As a result, they were routinely criticised within their disease groups for seemingly failing to remain self-motivated during difficult periods whilst others were able to. In this way, their lack of motivation was viewed as a personal failing rather than as a result of economic inequality.

Within both disease groups, disease advocates and medical staff often use those who can afford cutting-edge treatments and/ or expensive disease management practices as examples of how best to manage progressive symptoms without considering the relative advantages that they have that allow them to do so. In this way, those who cannot effectively manage their symptoms because they do not have the financial means to do so are marginalised within narratives that stress the importance of 'positivity' in overcoming some of the more challenging disease symptoms that participants face, such a s chronic pain and depression. The voices of those who are able to help themselves are heard whilst the voices of those who are unable to do so are silenced, which leaves many in the latter group feeling as though they have personally failed to overcome their symptoms.

Because the inequalities that exist within these groups in terms of treatment are largely systemic, feeling personally responsible for not living up to the standards of other more affluent people within their disease group cannot positively influence the outcomes of individuals who, by themselves, cannot change or shift wider social structures that perpetuate and sustain existing inequalities. When considering the degree to which participants should be held "responsible" for their health outcomes, it is important to consider the social, cultural and political circumstances of each participant and the extent to which they inform that person's ability to choose better ways of managing their health. To not do so would mean further invisibilising those who cannot assume personal responsibility within disease narratives that currently render them "unknowable" and "unseen."

Conclusion

> I think it's [AKU] a problem because it's not recognised. Because people don't believe you're ill or that you've got a problem. I mean yeah I was lucky and unlucky in some respects with work because for years I mean there were things going on but where I worked you know there was no problem with getting time off to go to various places to see doctors or consultants or whatever. But I did at one point have one line manager who was a terrible bully and who treated me very badly and you know always firmly believed that I wasn't in pain and that I was making it all up. Even when I'd had surgeries you know … because again it's the invisible thing, looking ok on the outside. So that can be kind of a curse, you know? Only with ignorant people though.
>
> (Lucy, AKU)
>
> Once I went to a job interview and I just showed up without my make up on, you know? When I do the job I'll wear the make up but when I'm not doing the job I'm just going to talk to you without it. And the guy who wanted to hire me was saying this is what I'm looking for but he wouldn't look at me. So then I'm looking around the office and I notice that when I look around his office he starts looking at me and I look back at him and he looks away from me. And when I look away from him he looks back at me and when I look back at him he looks away from me. And when I look down like I'm reading something he's looking at me again, he starts looking around my head taking an inventory I don't know and I look up and he looks away again. I met with the guy for 20 minutes and it was like that the whole time! He'll look at my eyes for like 2 seconds and look away and he'll start looking at his papers on his desk or he'll start reading like he's studying something and reading it to me and bla bla bla. And I'll look away and he's like staring at me. If his eyes were laser beams they would have burned a whole in the spots on my face, that's how hard he's looking at me. Like intense … trying to figure it out rather than asking.
>
> (Michael, vitiligo)

The above excerpts detail specific examples of common issues that participants from both disease groups often face in relation to their disease's relative (in)visibility. Lucy's inability to convince her employer that she was in pain because of her AKU was the direct result of his failure to see "evidence" of her condition. Even though she had

undergone a number of joint replacement surgeries because of her condition that rendered her temporarily immobile, her employer continued to assume that she "wasn't in pain" and was "making it all up." As a result, Lucy viewed her disease's "invisibility" as a "kind of curse" that prevented her from being seen and/ or taken seriously as someone with a debilitating condition that often rendered her incapable of working. For Michael, the high visibility of his condition on areas of his body that were easily seen by others (i.e. his face and hands) meant that his prospective employer could not see past his disease during his job interview. Upon contact with Michael the employer was unable to look at him for more than "2 seconds" before looking away, at which point he proceeded to stare at the "papers on his desk" until Michael looked away. After he saw that Michael's attention was no longer directed towards him he turned back and resumed staring at him. This "game" that Michael called "visual tennis" lasted throughout the duration of the interview, and left Michael feeling frustrated and concerned that he had not been able to demonstrate his suitability for the job because his vitiligo had distracted the man who was in charge of hiring him.

Both examples show how the relative (in)visibility of chronic disease symptoms can (and often do) serve as a barrier to one-on-one communication. Lucy was unable to communicate her pain to an unsympathetic employer who did not believe her because he could not see "evidence" of her pain and/ or of her AKU. Michael was unable to effectively communicate his experience and suitability for the job with a prospective employer who, because of his shock and curiosity about Michael's appearance, would not look directly at him when he was speaking. According to Michael, this was the principal reason why he was subsequently not offered the job. In addition, both examples show how having (in)visible disease symptoms can render that person "unseen" in relation to the way(s) in which they see themselves. For Lucy, this was as a person who frequently experienced pain and might need time off work in order to manage it, and for Michael this was as a person who had a disease that was wholly unrelated to his suitability for the advertised role. Both employers misread the participant's symptoms in relation to how the participants conceptualised them, and drew conclusions about the participant's (in)ability to carry out their jobs based on that misreading. As a result, Michael and Lucy were left feeling "unseen" by employers who considered them "unsuitable" and "lazy" respectively because of their visible and invisible symptoms.

Typically, vitiligo and AKU symptoms are visible and invisible respectively. When experienced by people of colour in particular, vitiligo is often immediately noticeable to onlookers because of the contrast between that person's "original" skin colour and their depigmented areas of skin. Dark urine and sweat and, later, chronic pain are the primary symptoms of AKU, and because all are relatively easy to conceal by patients who choose to modify their clothing choices and/ or behaviour accordingly, patients are

often able to pass as "normal"/ unaffected by their condition. However, the visibility of both conditions is largely dependent on both that person's disease stage and their ability to manage and/ or modify their symptoms. One of the vitiligo participants that I interviewed, Charles, was an African-American man who had recently founded a vitiligo support group in his local area. I agreed to meet Charles in a restaurant in South East Washington, DC and entered the restaurant at the agreed time. I had spoken with him briefly on the phone but I did not know what he looked like. I glanced around the restaurant expecting to see someone with vitiligo sitting alone but could not see anyone, and eventually a man who was sitting by himself but who showed no sign of having vitiligo gestured towards me. I later discovered that Charles had vitiligo on his chest, back and thighs, and that it had not yet spread to any visible parts of his body (i.e. his face or hands).

Because Charles covered these areas of his body with clothing, his vitiligo was invisible to those with whom he came into contact. As a result, Charles did not receive the same level of attention as those who had noticeable vitiligo on highly visible areas of their bodies (i.e. their face, neck or hands). Whilst most of the patients that I interviewed with AKU showed few outward signs of having the disease, two had extensive ochronosis on their face and hands and walked in a way that was suggestive of the fact that they had a physically debilitating medical condition.[90] One of these participants, Amy, picked me up from her local train station in a car that had been purposefully modified to suit her mobility needs, and drove me to her apartment that had also been personally modified in order to carry out the interview. As soon as she got out of the car I noticed that she walked "stiffly" and with difficulty, and when I looked at her directly I saw that she had ochronosis that was highly noticeable in her eyes, ears and on her hands. Amy remarked on her gait and her appearance at different points over the course of the interview, and discussed how they made her self-conscious about the way that she looked in general. She suggested that this, in turn, negatively affected her willingness to socially interact with other people.

Using Charles and Amy as examples, it is clear that vitiligo is not always "visible" and AKU is not always "invisible." Rather, the relative (in)visibility of both conditions is largely dependent on the disease's stage and the individual's ability to manage their symptoms on a day-to-day basis. When discussing his decision to undergo light box therapy in order to re-gain pigment in depigmented areas of his skin, Charles discussed how his medical insurers would not cover the full costs of this treatment, which meant that he had to independently finance most of it. If Charles was unable to meet these costs he would be unable to access this treatment, which, in turn, would mean that his vitiligo would likely progress to areas of his body that would make it more visible (i.e.

[90] These patients would often stumble or walk awkwardly, and would typically require some type of walking aid (i.e. a walking stick).

his face and hands). In other words, the relative invisibility of his disease as it progresses is largely dependent on his ability to acquire the necessary financial capital to manage it. At the time of the interview Amy was in her late 60s, and her AKU symptoms had progressed to the point where they were severely affecting her quality of life by rendering her incapable of working. Having worked hard her entire life in order to remain financially independent, Amy found this particularly difficult because it meant that she had to rely on the state for financial support. This, in turn, affected her mental health by making her feel "inadequate" and unable to control her life and her future. Whilst her circumstances made living with AKU particularly difficult, at the time of the interview Amy had settled in the UK where she was able to access Nitisinone through the National Health Service (NHS). This put her in an advantageous position when compared to her US counterparts, some of whom were in a similar financial position but were unable to access Nitisinone because their medical insurers refused to pay for it. Because she was able to access Nitisinone, Amy was able to lessen any damage that the disease would likely cause to her bones and joint cartilage in the future, which meant that she was able to prevent her disease symptoms from become *more* visible as she aged.

Participants from both disease groups who have (in)visible symptoms typically relate either wanting to resist their disease's "invisibility" by making their symptoms and/ or condition "known," or wanting to pass as "normal" or unaffected by it in order to render it "unknown." This contention is one that all participants discussed dealing with at some point over the course of their disease. Because both diseases are largely unknown, participants often expressed feeling that it was their "duty" to make the condition known in order to make having the disease "easier" for subsequent generations. Typically, this involved showing their disease symptoms to others and regularly discussing their disease symptoms with others on a casual basis. However, whilst members of both disease groups commonly expressed feeling this "duty," the motivations of each group varied considerably. Because most AKU patients were able to conceal evidence of their disease they were able to choose when and where to reveal it, and this meant that most patients only did so when they believed that it would directly impact policy decisions, funding etc. Moreover, because most of the patients who chose to do so were in their late 50s/ early 60s and had advanced (and irreversible) symptoms, these efforts were purposefully made for the benefit of future generations. In this way, their motivations for disclosing information about their disease was/ is primarily driven by a desire to seek immediate social and political gains for other patients at the point of disclosure.

However, for most vitiligo participants with highly visible symptoms, they are unable to choose when and where to reveal their vitiligo, which means that they are constantly seen in relation to it. Knowing that they are first "seen" as people with vitiligo, many

with this condition feel the need to demonstrate pride in having it in order to challenge the normalising gaze of the "other." In doing so they typically showcase their symptoms in a way that demonstrates their positive conceptualisation of it, with the aim of encouraging others who also have it to embrace the changes that the condition has made to their appearance in the same way. In making their bodies "visible," these people aim to create awareness for a condition that continues to remain "unseen" by many who either have not heard of it or who do not recognise its symptoms. In addition, by relating their struggles in coming to terms with having vitiligo over the course of their disease "journey," they seek to "visibilise" the everyday struggles of those who also have it but choose to remain socially isolated in order to avoid stares and negative attention from other people.

The (in)visibility of both diseases is also significantly influenced by instances of medical mistreatment and/ or neglect. As detailed in my chapter about personal responsibility, both Amanda and Amy experienced an exacerbation of their disease symptoms after being neglected by their primary care physicians and/ or the medical team that were in charge of their care. Amanda directly attributed the onset of her vitiligo to her nurse's decision to continue her steroid treatment for longer than was medically advised, and Amy discussed how her doctor's decision to involve the crisis team in her medical care worsened her overall health and made her concerned that she would not be able to regain control over her life after her health stabilised. Both participants were in positions of financial precarity as both were receiving disability benefits, and both alluded to the ways in which this might have affected their medical care at different points over the course of their interviews. The subsequent pain (both emotional and physical) that Amanda and Amy later experienced was attributed by both to their positionality as patients who, as marginalised subjects, seemed "not to warrant" good medical care from their doctors. For both, their specific needs as patients were overlooked and/ or "invisibilised" by medical practitioners who failed to acknowledge their needs in favour of their own personal agendas.

In seeking to make themselves and/ or their conditions "seen" or "unseen," participants from both disease groups often discussed what they felt to be a "need" to "perform" their disease by enacting certain tropes that onlookers expected of them. For AKU patients, this typically meant "exaggerating" their chronic pain to doctors who would then prescribe them pain relief. Although most patients had grown "accustomed" to their pain in a way that made it difficult for them to discern from feelings of "non-pain," they understood the importance of "showing it" when it would lead to pain relief medication. For people with vitiligo, their efforts to correct misperceptions about what their disease is and how it negatively affects those who have it typically results in a performance of "non-pain" that seeks to present it as a positive signifier of "beauty" and "uniqueness" rather than as a negative sign of disfigurement.

Whilst this thesis offers a useful and detailed account of the ways in which (in)visibility affects the everyday lives people living with AKU or vitiligo it is important to point out its limitations. Firstly, as outlined in my methodology chapter, I do not have either of these conditions, nor do I experience any of the common symptoms that participants described, such as chronic pain. As a result, my knowledge of the lived experiences of these participants, whilst detailed, does not come from any personal experiences that I have of managing either of these diseases on a day-to-day basis and, therefore, could be considered "limited." Secondly, I was unable to gather a range of perspectives from AKU patients who were from different racial and ethnic backgrounds. As a result, I was unable to detail the ways in which race or ethnicity might have influenced the day-to-day disease-related experiences that patients have. Thirdly, I was only able to interview vitiligo participants who had "made it through" the depression and anxiety that typically occurs immediately after diagnosis. As a result, I was unable to relate these experiences as they were felt at that moment, and had to rely on how participants remembered them. Because several of these participants received their vitiligo diagnosis decades before our interview took place, it was often difficult for them to describe in detail their immediate reactions to it.

However, despite these limitations this thesis has contributed to an existing body of literature concerning the politics of social (in)visibility and performativity in three key ways. Firstly, it is the first study to use AKU and vitiligo as comparative case studies. As I have consistently shown throughout this thesis, whilst these two diseases differ in terms of their aetiology, together they provide interesting insights into the ways in which disease visibility relates to social visibility, and the different mechanisms involved in the participant's decision to reveal their condition or pass as "unaffected" by it. Secondly, it is one of very few studies that considers social visibility in relation to passing, concealment and health. As previously discussed, most of the existing body of literature concerning issues related to passing refer specifically to race or gender and, consequently, often overlook the importance of health in discussions of what constitutes a "normative" body or appearance. Thirdly, it is one of a handful of studies that draws an explicit connection between social visibility and disease visibility. At the time of writing there are very few studies in this area, none of which use the same theoretical underpinnings as the ones that were used in this thesis.[91]

In light of the limitations of my research I suggest two primary areas of research that could be of interest to scholars who are working in this field. Firstly, one that offers a detailed exploration of the "absent presence" of people of colour in the US who are not being diagnosed with rare diseases like AKU. After completing an extensive literature review I was unable to uncover any studies that offered a clear and coherent analysis of

[91] In terms of drawing connections between Du Bois, Butler, Cooley, Foucault, Goffman etc.

this issue and further exploration is, I believe, crucial in order to understand why some groups are marginalised, excluded and, ultimately, invisibilised within discourses surrounding this topic. The second recommendation involves understanding the role that skin colour plays in the everyday lives of people with vitiligo. During their interviews numerous black participants discussed the variations in skin tone within the online black vitiligo community, and how differences in skin tone likely shaped the overall experiences of people with the disease. Studies that use skin colour as a variable to assess the everyday experiences of people living with vitiligo would, I believe, further enhance the existing scholarship in this area.

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Appendix

Appendix A – interview questions

1) What is your background? How old were you when you were first diagnosed with AKU/ vitiligo? How were you diagnosed?
2) How did you feel after gaining the diagnosis?
3) Have you had any particularly negative or positive experiences with doctors or medical specialists?
4) Have you had to undergo any medical procedures? If so, what impact has this had on the way you live your life (relationship with your family and friends etc.)?
5) Do you have any health complications that coincide with AKU/ vitiligo?
6) Have you had any issues with medical insurance?
7) How would you describe your quality of life with AKU/ vitiligo?
8) What impact would you say that having AKU/ vitiligo has had on your identity?
9) Are there any visible signs of your disease?
10) How do these visible signs (if any) make you feel?
11) Do you worry about these visible signs potentially progressing in the future?
12) Do any of the symptoms of AKU/ vitiligo make you self-conscious?
13) Do you use a walking stick or something similar and, if you do, do you mind using it? (For AKU patients)
14) Do you openly discuss the fact that you have this disease with other people?
15) Do people often stare at you? Are you constantly aware of this?
16) Are you constantly in pain? How do you deal with this?
17) Do you worry that one day you might need mobility aids i.e. a scooter, walking stick etc.? Why? (For AKU patients)
18) Have you ever tried to hide the fact that you have this disease from other people? Why/ why not? How?
19) Do you think that this disease would be easier or harder to deal with if you were a woman/ man?
20) Have you looked online at images of people with your disease? Why/ why not? If you did, how did seeing these images make you feel?
21) Would you want to see the ochronosis in your joints and bones if surgeons offered to take photographs of it? Why/ why not? (For AKU patients)
22) What is your occupation? When planning a career were you in any way mindful of the fact that you have AKU/ vitiligo?
23) Do you anticipate that having AKU/ vitiligo might prevent you from working one day? How does this make you feel?
24) Has AKU/ vitiligo stopped you from pursuing or continuing with a particular career?
25) Do you/ have you ever worried about how your disease might affect your relationships with other people? (i.e. marriage).
26) Do you ever feel pressured to just get on with life in spite of your disease and stop complaining about it?
27) Has anyone in your family been diagnosed with AKU/ vitiligo?
28) Do you worry about your children getting AKU/ vitiligo?
29) Do you worry about the future and your AKU/ vitiligo progressing? How do you cope with this?
30) Have you found it difficult to convince doctors that you are in pain/ emotionally distressed?
31) Have you ever felt like you've had to educate your doctors about AKU/ vitiligo?
32) Have you done anything to change your diet because of your diagnosis?
33) How helpful do you find online patient communities like patientslikeme, rare connect, and Facebook?
34) Are you hopeful that there will, one day, be a cure for AKU/ vitiligo?
35) What does being "healthy" mean to you?
36) What do you want other people to know about your experiences in living with AKU/ vitiligo?

Appendix B – consent form

Department of Sociology, University of Cambridge
INFORMED CONSENT FORM

Title of Project: US Patient Experiences of Living with AKU or Vitiligo

Name of Researcher: Tanisha Spratt

As part of a research project on the social experiences of those who are living with either AKU or vitiligo I am conducting interviews. You will be asked questions about your past and daily social experiences in living with your condition. This research is being conducted as part of a PhD course.

The interview will take around 40 minutes – 1 hour.

Please tick box

1. I confirm that I have understood these instructions and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. ☐

3. I understand that my responses will be anonymised and only used for academic research. ☐

4. I understand that my interview may be recorded. ☐

5. I agree to take part in the above project. ☐

6. I agree to the distribution of images that I have provided you with and approved ☐

_____ ____ _____
Name of Participant Date Signature

_____ ____ _____
Name of Researcher Date Signature